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AUTHOR Whitley, Elizabeth B.; Skiles, Laura Lopater
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ABSTRACT

This manual presents information about major causes of developmental disabilities, discusses strategies to prevent development disabilities, and identifies relevant resources and reference material. Introductory information defines developmental disabilities and prevention (under Virginia statutes). The first section considers causes prior to and during pregnancy, including genetic disorders, infectious diseases, other maternal conditions, nutrition, tobacco, alcohol, drugs, caffeine, environmental exposures, maternal age, and preterm labor. The second section looks at causes during infancy, childhood, and adolescence. These include metabolic disorders, infectious diseases, nutrition, alcohol and drug use, environmental exposures, unintentional injuries, and child abuse and neglect. The third section considers the development of prevention programs and projects, with guidelines addressing needs assessment, planning, evaluation, and critical data elements. The next section presents 43 tables of Virginia statistical data useful in evaluating prevention efforts. The last section presents summary information on 33 Virginia programs which focus on prevention either prior to and during pregnancy or infancy, childhood, and adolescence. References and recommended resources are listed for most sections. (DB)

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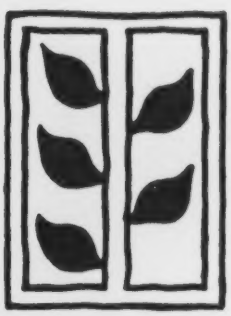
A MANUAL ON THE PRIMARY PREVENTION OF DEVELOPMENTAL DISABILITIES



VIRGINIA INSTITUTE FOR DEVELOPMENTAL DISABILITIES

University Affiliated Program
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A MANUAL ON THE PRIMARY PREVENTION OF DEVELOPMENTAL DISABILITIES

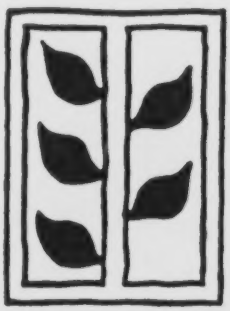
Prepared by:

Elizabeth B. Whitley, Ph.D.

and

Laura Lopater Skiles, M.S.

Developmental Disabilities Grant #91-03



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PRIMARY PREVENTION OF DEVELOPMENTAL DISABILITIES

INTRODUCTION

Developmental Disabilities

The recognization of and meeting the needs of persons with various mental and physical impairments/disabilities dates back many years. The Developmental Disabilities Services and Facilities Construction Act of 1970 was enacted to recognize and address the needs of a specific segment of the handicapped population, persons with developmental disabilities. The Act defined developmental disabilities both functionally and categorically, listing mental retardation, cerebral palsy, and epilepsy as the basic conditions of the target population, but also including other disabilities. Over the years the Act has been amended several times with the most current Act being the Developmental Disabilities Assistance and Bill of Rights Act of 1990 (Developmental Disabilities Office, 1991).

Developmental disability is defined in the Developmental Disabilities Assistance and Bill of Rights Act of 1990 as a severe, chronic disability of a person five years of age or older which:

1. is attributable to a mental or physical impairment or combination of mental or physical impairments;
2. is manifested before the person attains the age of 22;
3. is likely to continue indefinitely;
4. results in substantial functional limitations in three or more of the following areas of major life activity:

    a. self-care,
    b. receptive and expressive language,
    c. learning,
    d. mobility,
    e. self-direction,
    f. capacity for independent living, and
    g. economic self-sufficiency; and

5. reflects the person's need for a combination and sequence of special interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated;

except that such term when applied to infants and young children means individual from birth to age five, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with high probability of resulting in developmental

disabilities if services are not provided (Developmental Disabilities Office, 1991).

There are currently approximately 111,372 persons in Virginia with developmental disabilities (Developmental Disabilities Office, 1991). Many agencies and organizations at the federal, State, and local levels work in the area of developmental disabilities.

Prevention

The concept of prevention has been in existence many years. Its earliest history is linked to public health and many health-related areas. The United States Department of Health, Education, and Welfare (currently the Department of Health and Human Services) designated 1979 as its Year of Prevention. In the report Healthy People, the Surgeon General referred to prevention as an "idea whose time has come". Prevention saves lives, improves the quality of life, and saves dollars in the long run (Poe, 1982). Federal efforts in prevention have continued since 1979 and have been paralleled by efforts in Virginia. The United States Department of Health and Human Services defines prevention as interfering with the onset or progression of a condition and its related disability. The three levels of prevention are primary, secondary (intervention), and tertiary (treatment). Primary prevention seeks to avert the onset of a condition; secondary prevention is the early detection and intervention/treatment of a condition at high risk for disabilities; and tertiary prevention reduces the effects of the condition or disability (Committee on a National Agenda for the Prevention of Disability, Institute of Medicine, 1991).

The Code of Virginia, Section 9-270 defines prevention as activities which:

1. can promote the maximum independence of individuals and strengthen families;
2. avoid or minimize physical or mental disability or dysfunction;
3. reduce the likelihood of dependency on governmental and private sector support; and
4. encourage future cost savings through early intervention or treatment (Virginia Council on Coordinating Prevention, 1991).

This manual supports both of these definitions but confines its contents to primary prevention.

Many agencies at the federal, State, and local levels work in the area of prevention.

Prevention of Developmental Disabilities

Professionals and advocates indicate that over 50 percent of all developmental disabilities are preventable due to significant strides in a number of professional fields. Numerous

prevention strategies can be used prior to and during pregnancy which can increase the probability of a woman having a healthy baby. These strategies include prepregnancy testing to see if a woman (or a man) has a genetic disorder and genetic counseling of reproductive options; prepregnancy testing to see if a woman has had rubella; prepregnancy and during pregnancy testing to see if a woman has a sexually transmitted disease such as cytomegalovirus and herpes and treatment if necessary; educating women to stop tobacco, alcohol, and drug use prior to and during pregnancy; encouraging women to obtain early and adequate care during pregnancy; etc. There are also numerous prevention strategies that can be used after birth, during infancy, early childhood, and adolescence which can increase the probability of a child growing into a healthy adult. These strategies include newborn screening for conditions such as phenylketonuria (PKU), biotinidase deficiency, and hypothyroidism and treatment if necessary; inoculating children against diseases such as polio and measles; screening children for potential disabilities; educating parents about child abuse and neglect; educating parents and children about accidental poisoning including lead poisoning and injury; educating children about the harmful effects of alcohol and drugs; etc.

Research has shown that prevention strategies (preconception through adolescence - medical as well as social) do work and that it is less costly to implement prevention strategies than to provide treatment for developmental disabilities. Therefore, by investing resources in prevention strategies now while maintaining quality services to those persons having developmental disabilities, it is possible to reduce the number of persons having developmental disabilities in the future. Many agencies and organizations at the federal, State, and local levels work in the area of prevention of developmental disabilities. Some of the agencies and organizations are very visible and identified as dealing with the prevention of developmental disabilities, others are less visible and/or not specifically identified as dealing with the prevention of developmental disabilities but nevertheless are doing so. It is important to identify all agencies and organizations that in any way deal with the prevention of developmental disabilities and combine resources to establish a more comprehensive, cost effective effort.

The Manual

This manual is an information document and a working document. It serves to identify some of the major causes of developmental disabilities, to discuss strategies to prevent developmental disabilities, and to identify resources and reference material on the following topics:

- Prior To and During Pregnancy
  - Genetic Disorders
  - Infectious Diseases
  - Other Maternal Diseases/Disorders/Conditions

- Nutrition
- Tobacco/Alcohol/Drugs/Caffeine
- Environmental Exposures
- Maternal Age
- Preterm Labor

Infancy/Childhood/Adolescence

- Metabolic Disorders
- Other Conditions
- Infectious Diseases
- Nutrition
- Alcohol and Drug Use
- Environmental Exposures
- Unintentional Injuries
- Child Abuse and Neglect

This manual also briefly discusses how to do needs assessment, prevention program/projects development, and evaluation. Interagency/interdisciplinary programs/projects are stressed. The manual presents 43 data elements which can be used in needs assessments and evaluation efforts to prevent developmental disabilities and presents Virginia data on these data elements where available for the past six years (1984-1985 through 1989-1990). Finally, the manual presents a number of effective programs/projects for prevention of developmental disabilities that are in Virginia at the State and local levels.

References Used

Committee on a National Agenda for the Prevention of Disabilities, Institute of Medicine. (1991). Disability in America. Washington, D.C.: National Academy Press.

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PRIMARY PREVENTION OF DEVELOPMENTAL DISABILITIES

PRIOR TO AND DURING PREGNANCY

Overview

Ideally, pregnancy is planned. This provides the woman an opportunity to see a doctor before becoming pregnant. She should receive genetic screening and counseling if appropriate. She should be checked to see if she has been inoculated against infectious diseases such as rubella and to be inoculated if necessary; and to see if she has diseases or conditions such as sexually transmitted diseases , other infections, diabetes, phenylketonuria (PKU), etc. and to have them treated (cured or controlled) if possible. Planning also provides the woman an opportunity to ensure her diet is adequate for nutritional needs during pregnancy; to stop using tobacco, alcohol, drugs, and caffeine; and to avoid harmful environmental exposures. If the pregnancy is planned, the woman has an opportunity to obtain prepregnancy care as well as early and adequate prenatal care and to be prepared for pregnancy. It has been said that prepregnancy planning and pregnancy should be a 12 month process.

If the pregnancy is not planned, the woman should still obtain early and adequate prenatal care. The above strategies are important during pregnancy (as early as possible ideally) even if they didn't occur prior to pregnancy. The woman should maintain good health; have genetic screening and counseling if appropriate; see that diseases such as infections are avoided if possible; see that diseases or conditions present are treated (cured or controlled); maintain an adequate and appropriate diet; take vitamins and minerals if appropriate; avoid using tobacco, alcohol, and drugs; avoid harmful environmental exposures; take precautions against preterm labor; etc. Early and adequate prenatal care is essential. Preparation for childbirth and parenting is also essential.

It is also possible that complications could arise during labor and delivery to cause a developmental disability. The best strategy to attempt to avoid complications is for the woman to receive early and adequate prenatal care. By receiving this care, the woman will have records on her health and pregnancy and will have planned for her delivery. These records and this planning will help all involved in the labor and delivery to anticipate complications and avoid them if possible.

The above prepregnancy and pregnancy strategies should avoid problems if possible. If not, the strategies should detect problems early, correct or minimize them if possible, decrease the risk of complications during labor and delivery, and assist a woman in having a good pregnancy outcome - a healthy baby.

Genetic Disorders

I. Problem

Genetic disorders are disorders of the hereditary material - genes on the chromosomes. Genetic disorders in a family can be passed from generation to generation and can cause many disabilities including developmental disabilities. Genetic disorders can be categorized as follows:

A. Autosomal Dominant Disorders (single-gene)

1. Description

The child has inherited a single abnormal gene from the affected parent which is dominant over the normal gene inherited from the unaffected parent.

- Each child has a 50 percent chance of inheriting the dominant gene (thereby inheriting the disorder).
- Conversely, the child also has a 50 percent chance of receiving the normal gene of the affected parent, resulting in an unaffected child (Poe, 1982).

2. Distinctive Features of Autosomal Dominant Disorders

- Each affected child has an affected parent. Two unaffected parents cannot produce an affected child (unless the disorder in that child is a new mutation).
- New (de novo) mutations are important in accounting for new cases.
- Males and females are usually affected with equal frequency.
- Fathers and mothers can both pass on the disorder to a child.
- In general, if there is no clear pattern from one generation to the next, it is not likely an autosomal dominant disorder (Schild and Black, 1984).

3. Examples of Autosomal Dominant Disorders

- Achondroplasia: Disproportionate short stature with large head.

- Craniofacial Dysostosis: Developmental disorder of the face and skull that can result in mental retardation.

- Myotonic Dystrophy: Neuromuscular disorder with mask-like facial appearance and possible mental retardation.

- Osteogenesis Imperfecta Tarda: Brittle bones, hearing loss, and blue scleral.

- Neurofibromatosis: Cafe-au-lait spots and neurofibromas of the skin, brain, spinal cord, or blood vessels causing blindness, deafness, high blood pressure, and learning disabilities (Kolodny, et al., 1990) and (Action for Prevention, 1989).

B. Autosomal Recessive Disorders (single-gene)

1. Description

Both parents carry the same abnormal (recessive) gene. The child who receives an abnormal gene from each parent can have a significant genetic disorder.

- If both parents carry the abnormal gene there is a 25 percent chance that the child will have the disorder.

- If both parents carry the abnormal gene there is also a 75 percent chance that the child will not have the disorder.

- There is a 50 percent chance that a child will inherit a single abnormal gene from only one parent, thereby making him or her a carrier of the genetic disorder like his or her parents, but not being affected by the disorder (Poe, 1982).

2. Distinctive Features of Autosomal Recessive Disorders

- This is most commonly seen in a single generation as an isolated, affected child (i.e., often difficult to distinguish from an environmental cause or a new mutation).

- Most affected children result from matings between totally healthy carrier parents.

- Males and females are usually affected with equal frequency.

- Increased incidence is seen in consanguineous matings.

- Increased incidence is seen in inbred/genetically isolated population (Schild and Black, 1984).

3. Examples of Autosomal Recessive Disorders

- Tay-Sachs: Progressive neurologic deterioration causing blindness and early death usually in children of parents who are of eastern European Jewish descent.

- Thalassemia: Severe fatal anemia usually in children of parents of Mediterranean descent.

- Phenylketonuria (PKU): Metabolic disorder which, if untreated by dietary methods, produces mental retardation.

- Cystic Fibrosis: A metabolic disorder resulting in inefficiency of secretion control in the lungs, pancreas, salivary glands, intestines, and liver.

- Galactosemia: Enzyme metabolism disorder which can cause damage to the infant's liver, spleen, and eyes and can cause metal retardation.

- Biotinidase Deficiency: Metabolic disorder which, if untreated, causes mental retardation.

- Sickle Cell Anemia: Painful disorder due to abnormal hemoglobia in red blood cells that can affect almost every part of the body and its systems that occurs primarily among Afro-Americans (Whaley and Wong, 1987) and (University of Colorado Health Sciences Center, 1988).

C. X-Linked Recessive Disorders (single-gene)

1. Description

An abnormal gene is located on one of the X sex chromosomes, either on one of the two X chromosomes from the mother, or, on the X chromosome from the father.

- Thus far no harmful genes have been discovered on the Y chromosome from the father.

- Since the male has only one X chromosome, any abnormal gene on that chromosome, even if it is recessive, will produce the disorder.

- If the female has a normal gene on one X chromosome to counter the abnormal recessive gene on the other X chromosome, then she is a carrier of the disorder but does not have the disorder herself.

- The affected male passes his abnormal X chromosome to his daughters.

- Sons of a father with a X-linked disorder cannot inherit the disorder from him. Neither can any descendants of this son.

- None of the affected father's daughters will inherit the disorder either, if their mother does not have the same abnormal gene. However, these daughters will be carriers.

- In the most common form, one X chromosome of an unaffected mother carries one abnormal gene (X) and the other X chromosome carries a normal one X. The father has normal X and Y chromosomes. In this form:
  The odds for each male child are 50-50:

  1. 50 percent risk of inheriting the abnormal X gene and the disorder and the normal Y chromosome.
  2. 50 percent chance of inheriting normal X and Y genes.

  For each female child, the odds are:

  1. 50 percent risk of inheriting one abnormal X gene, and normal X chromosome to be a carrier like her mother.
  2. 50 percent chance of inheriting no abnormal X gene (both normal X chromosomes).

- There can be new mutations (Schild and Black, 1984), (Kolodny, et al., 1990), and (Poe, 1982).

2. Distinctive Features of X-Linked Recessive Disorders

   - Females most frequently are the carriers and are not affected by the abnormal gene.

   - Mother carriers have a 50-50 chance of having an affected son, regardless of the father being genetically normal.

   - There appears to be skipping of generations, i.e., alternation between carrier mother and affected son.

   - New mutations are important in accounting for new cases (Schild and Black, 1984).

3. Examples of X-Linked Recessive Disorders

   - Color Blindness: Disorder which interferes with seeing colors - primarily reds and greens.

   - Duchenne Muscular Dystrophy: Slow progressive damage to the muscles supporting the skeleton leading to early death because of respiratory muscle function.

   - Hemophilia A and B: Deficiency in the blood results in this excessive bleeding disorder (Whaley and Wong, 1987).

D. Multifactorial Disorders

1. Description

   The disorder is the result of the interaction of many predisposing genes and unknown environmental factors (Poe, 1982).

2. Distinctive Features of Multifactorial Disorders

   - There is an increased risk for recurrence of a disorder among first, second, and third degree relatives of an affected person.

   - For most of the more common disorders of this type of inheritance, there is a risk of two to five percent for first-

degree relatives, one-half that risk for second-degree relatives, and one-fourth for third-degree relatives.

- Risk increases with increasing numbers of affected, genetic relatives, especially among first- and second-degree relatives.

- Risk increases if the affected person is of the sex less frequently affected.

- Risk increases with increasing severity (Schild and Black, 1984).

3. Examples of Multifactorial Disorders

- Cleft Lip with or without Cleft Palate: The failure of the two sides of the upper lip to grow together, and/or a split or opening in the roof of the mouth.

- Club Foot: An awkward, twisted position of one or both feet, that cannot be stretched or turned back to normal placement.

- Neural Tube Defects (such as Spina Bifida): A defect in the bony structure of the spinal column, through which some of the spinal cord has slipped out to form a cyst or a lump on the back (University of Colorado Health Sciences Center, 1988).

E. Chromosome Disorders

1. Description

These disorders involve abnormality in either the number or the structure of the chromosomes.

- Abnormalities in number include either extra or missing chromosomes.

- Abnormalities of structure include deletions, duplications, or inversions of chromosome material or translocation of material from one chromosome to another (Kolodny, et al., 1990).

2. Distinctive Features of Chromosome Disorders

- Disorders of chromosomes occur with considerable frequency. Fifty percent of spontaneous abortions show chromosomal abnormality.

- Major defects in the chromosomes numbered one through 12 result in such marked disorders in the fetus that it is usually spontaneously aborted.

- When defects occur in the other autosomal pairs (most likely pairs 13,14,15,18 and 21) the fetus may be carried to term or near term, and be born with a number of serious physical disorders and mental retardation which is usually moderate to severe.

- Defects in the sex chromosomes are also sometimes associated with mental retardation (Fotheringham, et al., 1983).

3. Examples of Chromosome Disorders

   - Down Syndrome: Usually an additional chromosome on the 21st pair (also known as trisomy 21) resulting in mental retardation, cardiac problems, and several skeletal abnormalities. Risk factors in Down syndrome are:

     - Advanced Parental Age: The chances of having a child with Down syndrome rise with parental age. Chromosome problems tend to increase in older women. The chances of having a child with Down syndrome increase when the woman reaches age 35 and these chances continue to rise with increasing maternal age. Paternal age has also been linked to Down syndrome as well. Incidence increases slowly for fathers up to age 45 and rises dramatically past the age of 55.

     - Pregnant women with Down syndrome have a 50 percent chance of passing this disorder to the fetus.

     - Women who have experienced repeated miscarriages are at greater risk for having a child with Down syndrome.

- Fragile X Syndrome: An alteration in the X chromosome that is due to structural and functional changes of a gene and its expression, resulting in mental retardation primarily in males, but also potentially mental deficiency in female carriers.

- Cri-du-Chat Syndrome: Partial deletion of a portion of chromosome five resulting in feeding difficulties, a distinctive infant cry due to underdevelopment of the voice box, and severe mental retardation (Action for Prevention, 1989) and (Poe, 1982).

II. Prevention Strategies

A. Preconceptual Genetic Screening and Counseling

- Genetic screening and counseling prior to conception is important preparation for parenthood. As a result of this process, genetic disorders within a family can be identified and the risk of recurrence can be estimated. The goal of genetic screening and counseling is to reduce the probability that serious and life-threatening disorders will occur or recur within the same family.

- Often the geneticist and/or the genetic counselor work in conjunction with other health care professionals such as the obstetrician, pediatrician, and/or family practitioner. In many cases, these are the professionals who refer the person for genetic screening and counseling. Table 1 lists groups of persons for whom genetic counseling may be indicated (Kolodny, et al., 1990).

Table 1 Indications for genetic counseling

- Parents who have had a child with a birth disorder or inherited disease
- Persons with a birth disorder or inherited disease themselves, or other family members with the disorder or disease
- Women over 35
- Persons who are members of ethnic groups with a high incidence of a particular inherited disease (e.g., Tay-Sachs in Jewish people, Sickle Cell Anemia in Afro-American people, Thalassemia in people of Mediterranean origin)
- Couples with a history of repeated miscarriage, stillbirth, or early infant death
- Couples who have or are planning a consanguineous marriage (e.g., a marriage of first cousins)
- Persons with a history of excessive exposure to drugs, chemicals, or radiation

B. Prenatal Genetic Diagnosis

- Prenatal genetic diagnosis and counseling is important for the same persons listed in Table 1 above. Some of the more common techniques for prenatal genetic diagnosis are:

  1. Amniocentesis: Probably the best known technique for prenatal genetic diagnosis, this procedure involves withdrawing amniotic fluid between the 14th and the 16th week of pregnancy. The fetal cells present in the sample are then grown in cultures and used for DNA, cytogenetic, and/or biochemical analyses. Use of cytogenetic analysis can uncover chromosomal abnormalities of number and structure. There are also approximately 100 metabolic disorders that can be identified using amniotic fluid cells.

  2. Ultrasonography: Low energy, high-frequency sound waves are used to visualize intrauterine structures. It is often used in conjunction with amniocentesis. Ultrasonography is a reliable diagnostic procedure for determining fetal malformations such as neural tube defects and pregnancy with elevated alpha fetoprotein.

3. Chorionic Villus Sampling (CVS): The newest procedure to determine first-trimester prenatal genetic diagnosis. This procedure involves sampling tissue from the placenta at eight to 12 weeks of gestation. The cells obtained can be used for cytogenetic, DNA and biochemical studies.

4. Maternal Serum Alpha Fetoprotein (MSAFP): Alpha fetoprotein (AFP) is a substance produced by the liver of the fetus that also passes into the mother's bloodstream. The concentration rises gradually until late in pregnancy and can be measured by taking a sample of the mother's blood, or the amniotic fluid around the 16th week of pregnancy. Among the more severe problems are neural tube defects, brain (anencephaly), spinal cord (spina bifida), and abdominal wall (omphalocele) defects. These malformations allow an excess amount of AFP to leak into amniotic fluid and maternal blood (elevated MSAFP blood test). This test does not diagnose a birth disorder; it can only suggest special risk. Although approximately 50 out of every 1,000 will have an abnormal result, only one or two of them will have a fetus with a birth disorder. Repeating the MSAFP test and more extensive ultrasonography study usually follow the initial elevated MSAFP test.

   Low MSAFP readings are sometimes associated with chromosomal abnormalities, such as Down syndrome. However, a low MSAFP level does not seem to be as accurate a predictor of chromosomal abnormalities as a high level is of neural tube defects. Only one quarter to one third of fetuses with chromosomal abnormalities are identified with MSAFP screening.

   A newer screening test measures MSAFP levels along with the levels of two pregnancy hormones - estriol (a type of estrogen) and human chorionic gonadotropin (HuCG). This test, also called "The Trosomy Profile", appears to be more accurate than MSAFP alone in detecting Down syndrome. These three tests permit detection of 80 percent of neural tube defects and 60 to 70 percent Down syndrome fetuses. Fetuses with Down syndrome characteristically have increased levels of HCG together with low readings of AFP and estriol. The effectiveness of this profile test is still being studied, and there is uncertainty as the pathophysiology of these readings. Research also suggests that other chromosomal

abnormalities, particularly trisomy 18, have very similar reading patterns as those found in a Down syndrome evaluation.

5. DNA Technology Methods: These are new applications for amniotic fluid cells. Using techniques that can identify structural changes in a gene or in DNA, genetic disorders can be identified using any cell type. Over 50 genetic disorders have become identifiable through this method of technology including cystic fibrosis, Huntington disease, neurofibromatosis, thalassemia, hemophilia types A and B, phenylketonuria, Duchenne and Becker muscular dystrophies, and myotonic dystrophy. DNA analysis now makes it possible to identify over 45 genetic disorders where the specific mutation is known. With the expansion in this field it is likely that the number of diagnosable genetic disorders will increase in the future.

Each of the aforementioned techniques for prenatal genetic detection has a cost either in terms of risk to the mother and/or the fetus or financially and therefore should be used in situations where a birth disorder or malformation is suspected due to the identification of the couple being at risk. Couples may be viewed as being at risk if they fit into any one or more of the categories in Table 1 (Miller, 1990) and (Action for Prevention, 1989).

III. References and Resources

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B. Resources

Virginia Department of Health

Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services

Genetics programs at:

Medical College of Virginia, Virginia Commonwealth University in Richmond
University of Virginia in Charlottesville
Genetics and IV F Institute in Fairfax
Medical College of Hampton Roads in Norfolk
Virginia Sickle Cell Anemia Awareness Program in Richmond

March of Dimes

ARC (Association of Retarded Citizens)

C. Other References and Resources (complete with your own)

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Stine, Gerald J. (1989). The New Human Genetics. Debuque, Iowa: William C. Brown.

Whitley, Elizabeth B. (ed). (1991). Monograph on A Genetics Colloquium. Richmond: Virginia Institute for Developmental Disabilities.

Infectious Diseases

I. Problem and Prevention Strategies

There are a number of infectious diseases that if contracted by the woman prior to or during pregnancy can cause developmental disabilities. Some of these are as follows:

A. Rubella (German or Three Day Measles)

1. Description

- In order for a pregnant woman to contract rubella, she must be exposed to someone who has rubella during its contagious time and not have immunity from the disease via previous infection or immunization. The virus then produces an infection within the placenta which is then transmitted to the growing embryo or fetus. The incidence of infection is greatest during the first four to five months of pregnancy, with the greatest risk during the first eight weeks of gestation.

- If the embryo/fetus is infected with rubella, miscarriage, stillbirth, or multiple congenital abnormalities can occur in a live born infant. The most common symptom of congenital rubella is low birth weight. Many infants have cataracts in one or both eyes. Sensorineural hearing loss often affecting both ears is another manifestation. Heart defects, cerebral palsy, and mental retardation can also occur (Poe, 1982) and (Pueschel, et al., 1990).

2. Prevention Strategies

- Pregnant women should avoid contact with people who have rubella.

- Rubella is the major cause of congenital infection causing developmental disabilities which can be prevented by active immunization. Through the use of vaccine, the United States has seen a decline in the occurrence of congenital rubella and its effects by preventing epidemics, although isolated cases are still reported.

- The rubella vaccine is recommended for children of one year of age or older. A single immunization is usually administered

at approximately 15 months of age to prevent rubella, mumps, and rubeola. Therefore, most children today are immunized against rubella. Some states require that a child be immunized before entering the school system. Virginia law requires that children be immunized against rubella, mumps, and measles before two years of age. This law also states that local health departments administer these vaccines to all children free of charge. Virginia law also requires parents or guardians to produce certificates of immunizations when registering the child for school.

- In spite of these laws, many adolescents and adults today have not been immunized against rubella and therefore are not protected from contracting it. They should be immunized.

- Cases of rubella should be reported to public health departments in order to organize immunization programs so that small outbreaks do not become major epidemics.

- Since the live rubella virus is in the serum of the rubella vaccine it is recommended that the vaccine not be administered to pregnant women or during a three-month period prior to pregnancy. It should, however, be administered to women who are planning to become pregnant sometime in the future (Pueschel, et al., 1990), (Poe, 1982), and (Hinman, 1990).

B. Cytomegalic Inclusion Disease (Cytomegalovirus)

1. Description

- Congenital cytomegalovirus infection (CCI) is a viral infection which is passed on to the fetus either through the placenta near the time when the mother contracts cytomegalic inclusion disease, or during the birthing process.

- This disorder is so mild in adults and children that there are no symptoms. It is an infection with no seasonal variation.

- CCI can cause small or large head circumference in infants, damage to the retina of the eye, blindness, hearing loss, an enlarged liver and spleen, psychomotor delay, mental retardation, etc. (Pueschel, et al., 1990).

2. Prevention Strategies

. Pregnant women should avoid contact with people who are infected and their secretions.

. Pregnant women who work with children should be particularly careful since often children are affected and show no symptoms.

. Good hygiene.

. A CCI vaccine is being researched and tested (Pueschel, et al., 1990) and (Fotheringham, et al., 1983).

C. Herpes Simplex Virus - Type 2

1. Description

. Herpes simplex virus (HSV) infection during pregnancy is thought to cause miscarriage and birth disorders. A fetus can contract this infection by passing through the infected birth canal of the mother.

. The infant with HSV can have localized skin lesions, respiratory distress, enlarged liver, jaundice, bleeding, convulsions, lethargy, and eye complications.

. HSV occurs throughout the world without seasonal variation or an epidemic cycle.

. The attack rate of HSV type 2 (genital) is a reflection of sexual activity (Pueschel, et al., 1990) and (Fotheringham, et al., 1983).

2. Prevention Strategies

. Uninfected pregnant women (as well as all sexually active women) should be careful about their sexual practices to protect themselves against contracting HSV.

. Infected pregnant women should be carefully monitored, especially during the last eight weeks of pregnancy.

- Positive viral cultures or observed lesions are considered to be cause for a cesarean section delivery.

- If an infant is born vaginally to a mother with severe genital HSV, it is necessary to isolate the baby from other infants. This infant is usually isolated for a period of two weeks. It is also recommended that infants born by cesarean section should also be separated from other infants and followed closely by a pediatrician for one month.

- There has been some research on the use of various drugs on infants born with congenital HSV infection to reduce death and disabilities (Pueschel, et al., 1990) and (Fotheringham, et al., 1983).

D. Toxoplasmosis

1. Description

- Toxoplasmosis is a parasitic infection often passed to humans through infected fecal matter of cats, raw or poorly cooked meat, or raw goat's milk.

- In congenital toxoplasmosis, the main area affected by the disease is in the central nervous system which can result in hydrocephalus (increased fluid in the brain and an enlarged head), mental retardation, seizures, eye problems, and cerebral palsy (Pueschel, et al., 1990) and (Fotheringham, et al., 1983).

2. Prevention Strategies

- Pregnant women should avoid cats shortly before and during pregnancy. If the woman has a cat as a pet, someone else should clean the cat's litter box.

- Pregnant women should avoid eating raw meat or meat that has not been thoroughly cooked. It is also advised that pregnant women should wash their hands with soap after handling raw meat. Because freezing will kill the parasitic organisms, it is safe for pregnant women to handle and eat meat that has been frozen (Pueschel, et al., 1990) and (Fotheringham, et al., 1983).

E. Human Immunodeficiency Virus

1. Description

- Human immunodeficiency virus (HIV) is the virus that results in acquired immunodeficiency syndrome (AIDS). This disease has been reported worldwide with the number of reported cases increasing in epidemic proportions.

- Pediatric HIV is usually acquired from the mother during pregnancy.

- The incubation period for AIDS is variable. Most children born with HIV infection show symptoms within the first two years of life, however, some children have shown no symptoms for as long as seven years.

- Common symptoms of HIV in children include failure to thrive, inflammation of the lymph nodes, and fevers. As seen in adults, pneumonia is a common infection which affects children with HIV as well. HIV infected children are more likely than infected adults to be plagued by recurrent bacterial infections putting them at risk for sepsis and meningitis. Fungal infections of the mouth and esophagus are also common. HIV causes infection in the central nervous system which can result in developmental delays, mental retardation, small head circumference, and cerebral atrophy. It causes early death (Pueschel, et al., 1990) and (Ellis, et al., 1990).

2. Prevention Strategies

- Uninfected pregnant women (as well as all sexually active women) should be careful about their sexual practices to protect themselves against contracting HIV. They should also avoid IV drug use.

- At this time, the main means of prevention of congenital HIV is through preventing pregnancy in HIV infected women. The major problem with this method is that many of these women are unaware that they carry the infection, thereby unknowingly pass it on to the embryo/fetus. Thus, efforts in HIV-AIDS education and identification of at-risk women must become intensive.

. A number of drugs are being used and tested to delay on-set of AIDS once there is HIV infection (Pueschel, et al., 1990) and (Ellis, et al., 1990).

F. Other Infectious Diseases

. There are other infectious diseases which should be avoided during pregnancy if possible and treated if acquired during pregnancy. A number of these infectious diseases have vaccines to prevent them. These diseases can cause various problems to the fetus and infant. They are influenza, mumps, rubeola (red or 10 day measles), chicken pox, hepatitis, syphilis, gonorrhea, etc. (Peuschel, et al., 1990) and (Ellis, et al., 1990).

II. References and Resources

A. References Used

Ellis, George L.; Melton, James; Filkins, Karen. Viral Infections During Pregnancy: A Guide for the Emergency Physician. Annals of Emergency Medicine, July, 1990, 802-811.

Fotheringham, John B.; Hambley, Walther D.; Haddad-Curran, Harriet W. (1983). Prevention of Intellectual Handicaps. Toronto: The Martin Group.

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Poe, Elisabeth S. (1982). Prevention of Mental Retardation - A Manual for Community Program Development. Charlottesville: Region Ten Community Services Board.

Pueschel, Siegfried M.; Scola, Patrica S.; McConnel, Kim S. (1990). Infections During Pregnancy. In Siegfried M. Pueschel and James A. Mulick (eds.), Prevention of Developmental Disabilities. Baltimore: Paul H. Brookes Publishing Company.

B. Resources

Virginia Department of Health

Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services

AIDS Hotline 1-800-533-4148, Virginia Department of Health

Regional Perinatal Centers
- Medical College of Virginia, Virginia Commonwealth University in Richmond
- University of Virginia in Charlottesville
- Fairfax Hospital in Falls Church
- Roanoke Memorial Hospital in Roanoke
- Virginia Baptist Hospital in Lynchburg
- Children's Hospital of the King's Daughters and Sentara Norfolk General in Norfolk

Baby Care Program under Virginia Department of Medical Assistance Services

C. Other References and Resources (complete with your own)

Other Maternal Diseases/Disorders/Conditions

I. Problem and Prevention Strategies

There are several other maternal diseases/disorders/conditions that if in existence during pregnancy can cause developmental disabilities. Some of these are as follows:

A. Maternal PKU

1. Description

- Infants of women with phenylketonuria (PKU) are potentially subject to the adverse effects of high maternal phenylalanine levels during pregnancy. These are women who were identified with PKU at birth and maintained on a low phenylalanine diet.

- Women with PKU are at risk for miscarriage. Infants born to women with PKU show a variety of birth disorders including mental retardation, small head circumference, congenital heart disease, and prenatal onset growth deficiency. Later problems include seizures and spasticity (Hoyme, 1990).

2. Prevention Strategies

- The goal of managing maternal PKU pregnancies is to be aware of the condition prior to pregnancy and maintain a low phenylalanine diet preceding and throughout the gestational period in order to reduce risks to the embryo/fetus (Hoyme, 1990).

B. Toxemia (Preeclampsia)

1. Description

- This disorder is characterized by the sequential onset of fluid retention, high blood pressure, and excretion of protein in the urine of the pregnant woman. This occurs after 24 weeks of gestation. If this disorder is diagnosed and treated, the more severe form, eclampsia, can be prevented. Eclampsia is the most serious hypertensive condition of pregnancy. It is characterized by severe preeclampsia with the added risk of

maternal seizures and coma.

- The reported effects of this condition are a frequency of stillbirths, premature births, low birth weight, and congenital malformations (Fotheringham, et al., 1983).

2. Prevention Strategies

- Although preeclampsia cannot be prevented, it can be diagnosed early and treated. Treatment includes supervised diet, bed rest, and careful monitoring throughout pregnancy.

- Women who are predisposed to preeclampsia can be identified by the following: youth or older maternal age (35-40), first pregnancy, diabetes, multiple pregnancy (twins), poverty, poor nutrition, and emotional stress (Fotheringham, et al., 1983).

C. The Rh Factor

1. Description

- The Rh hemolytic disease of the newborn is caused by the excessive destruction of fetal and newborn red blood cells by maternal antibodies. A mother who has Rh negative blood (Rh-) becomes sensitized and develops antibodies against Rh positive (Rh+) blood. This can occur either through a mismatched blood transfusion, or a pregnancy with an Rh+ fetus (the father being Rh+). The maternal Rh+ antibodies cross the placenta and destroy fetal Rh+ red blood cells.

- If this disease goes undetected, it can cause stillbirth or death shortly after birth. If left untreated, it can cause deafness, mental retardation, and cerebral palsy.

- Rh incompatibility is not a problem for the first child but can be a problem for future children (Fotheringham, et al., 1983) and (Poe, 1982).

2. Prevention Strategies

- This condition is completely preventable. Women should have their blood typed to see if they are Rh-.

- Rh- women should be given Rh anti- immune globulin (Rho Gam Rho (D)) after exposure to Rh+ antigens. Antibody production can then be averted. Thus, Rh-mothers must receive the anti-immune globulin no later than 72 hours after delivering an Rh+ infant, a miscarriage, an induced abortion, termination of an ectopic pregnancy, amniocentesis, or an Rh+ blood transfusion...after every possible exposure to Rh+ blood (Fotheringham, et al., 1983), (Poe, 1982), and (Hoyme, 1990).

D. Maternal Diabetes

1. Description

- Pregnancy causes a number of complex metabolic changes in the pregnant woman to meet the needs of the developing fetus. One such change may be a disturbance in insulin production. This can precipitate diabetes in susceptible women and aggravate prepregnancy diabetes. Diabetes is associated with a high incidence of perinatal death and birth disorders including neural tube defects. Often death of the infant is due to these birth disorders.

- Infants born to diabetic women may be large, often exceeding 10 pounds at birth. Heart and skeletal defects are also common, as well as respiratory distress syndrome (a severe lung and breathing disorder that can appear immediately after birth). Other frequent complications include: jaundice, hypoglycemia (low blood sugar), and various neurologic, often convulsive disorders. These infants may have suffered from undernutrition while in the womb and therefore are in danger of mental retardation due to underdevelopment of the brain.

- There are two types of maternal diabetes. The first type is that of chemical or gestational diabetes. This is usually the milder form of the two types and is diagnosed through urine and blood samples taken from the pregnant woman. This milder form of the disease is usually less serious to the mother but leaves the fetus at greater risk due to the delay in diagnosis.

- The second type of maternal diabetes is one in which symptoms have been shown prior to pregnancy. The diabetes

may or may not be insulin dependent prior to pregnancy. Insulin dependent women and women who have had diabetes for a number of years are at high risk of having children with birth disorders. This type of diabetes can cause the pregnant woman to suffer from visual difficulties and toxemia (Poe, 1982), (Evard and Scola, 1990), and (Fotheringham, et al., 1983).

2. Prevention Strategies

. While it is not possible to prevent maternal diabetes, it is possible to reduce the effects the disease has on the fetus and in fact most diabetic women can have healthy infants.

. There should be:

. careful preconceptual planning by diabetic women,
. early diagnosis of maternal diabetes, and
. skillful obstetrical management throughout the pregnancy (Fotheringham, et al., 1983).

E. Anemia

1. Description

. This disorder is a deficiency in the oxygen-carrying material of the blood measured in concentration of hemoglobin, red blood cell volume, and red blood cell count. Pregnant women are particularly susceptible to this disorder because of an increase in their blood volume. Iron deficiency is the most common cause of anemia in pregnant women. Folic acid deficiencies can also cause anemia (Von Oeyen, 1990).

2. Prevention Strategies

. Anemia can be prevented as well as treated by supplementing the prepregnant and pregnant woman's diet with vitamins and minerals including iron and folic acid.

. Pregnant women should have blood screening for anemia (Von Oeyen, 1990).

II. References and Resources

A. References Used

Evrad, John R. and Scola, Patricia S. (1990). In Siegfried M. Pueschel and James A. Mulick (eds.), Prevention of Developmental Disabilities. Baltimore: Paul H. Brookes Publishing Company.

Fotheringham, John B.; Hambley, Walter D.; Haddad-Curran, Harriet W. (1983). Prevention of Intellectual Handicaps. Toronto: The Martin Group.

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Poe, Elisabeth S. (1982). Prevention of Mental Retardation - A Manual for Community Program Development. Charlottesville: Region Ten Community Services Board.

Von Oeyen, Paul T. (1990). Optimal Prenatal Care. In Siegfried M. Pueschel and James A. Mulick (eds.), Prevention of Developmental Disabilities. Baltimore: Paul H. Brookes Publishing Company.

B. Resources

Virginia Department of Health

Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services

Regional Perinatal Centers

- Medical College of Virginia, Virginia Commonwealth University in Richmond
- University of Virginia in Charlottesville
- Fairfax Hospital in Falls Church
- Virginia Baptist Hospital in Lynchburg
- Roanoke Memorial Hospital in Roanoke
- Children's Hospital of the King's Daughters and Sentara Norfolk General in Norfolk

American Diabetes Association - Virginia Chapter 1-800-582-8323

C. Other References and Resources (complete with your own)

Nutrition

I. Problem

- A woman's nutrition during pregnancy affects the fetal brain development and birth weight of the infant.

- Proper fetal growth depends on adequate nutrition. If a pregnant woman is malnourished, there will not be proper fetal growth. Fetal malnutrition leads to reduced growth in all internal organs, including the brain. It also leads to low birth weight.

- Low birth weight (weight less than 2500 grams or 5 1/2 pounds at birth) infants are at risk of neonatal death, poor infant development, mental retardation, motor dysfunction, neurological abnormalities, poor body growth, and increase illnesses (Poe, 1982) and (Fortheringham, et al., 1983).

II. Prevention Strategies

- Women at risk of nutritional problems are the very young, the economically deprived, those underweight at the beginning of pregnancy, those on special diets due to food fadism, those with pre-existing medical conditions such as diabetes who may or may not be on special diets, and those who abuse alcohol and drugs.

- Particular attention should be given to pregnant women at risk of nutritional problems, but all women should receive nutritional counseling.

- Adequate and proper diet is important during pregnancy.

- Supplemental vitamins and minerals (particularly iron and folic acid) are important during pregnancy (Poe, 1982), (Fotheringam, et al., 1983), and (VonOeyer, 1990).

III. References and Resources

A. References Used

Fotheringham, John B.; Hambley, Walter D.; Haddad-Curran, Harriet W. (1983). Prevention of Intellectual Handicaps. Toronto: The Martin Group.

Poe, Elisabeth S. (1982). Prevention of Mental Retardation - A Manual for Community Program Development. Charlottesville: Region Ten Community Services Board.

Von Oeyer, Paul T. (1990). Optimal Prenatal Care. In Siegfried M. Pueschel and James A. Mulick (eds)., Prevention of Developmental Disabilities. Baltimore: Paul H. Brookes Publishing Company.

B. Resources

Virginia Department of Health

Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services

Regional Perinatal Centers

- Medical College of Virginia, Virginia Commonwealth University in Richmond
- University of Virginia in Charlottesville
- Fairfax Hospital in Falls Church
- Virginia Baptist Hospital in Lynchburg
- Roanoke Memorial Hospital in Roanoke
- Children's Hospital of the King's Daughters and Sentara Norfolk General in Norfolk

WIC Program (Supplemental Food Program for Women, Infants, and Children) under Virginia Department of Health

Food Stamp Program under Virginia Department of Social Services

Baby Care Program under Virginia Department of Medical Assistance Services

C. Other References and Resources (complete with your own)

Institute of Medicine. (1990). Nutrition During Pregnancy. Washington, D.C.: National Academy Press.

Tobacco/Alcohol/Drugs/Caffeine

I. Problem

The use of tobacco (particularly cigarettes), alcohol, and drugs (including prescription drugs, over-the-counter drugs, and illegal drugs) by pregnant women can cause developmental disabilities. Information is as follows:

A. Tobacco

- Many studies indicate that cigarette smoking during pregnancy results in low birth weight infants. Infants born to women who smoke, on average, are six to eight ounces lighter than those of non-smoking women.

- A relationship between the amount smoked and reduced birth weight has also been found. For example, if a woman stops smoking early in her pregnancy, her risk of giving birth to a low birth weight infant nears that of a non-smoker.

- The pattern of fetal growth retardation associated with maternal smoking effects all areas of growth, including body length, chest circumference, and head circumference.

- The risk of miscarriage for a woman who smokes is nearly double than for non-smoking women.

- Early separation of the placenta is a risk for smoking women.

- Nicotine and carbon monoxide have been found to constrict both maternal and fetal blood vessels thereby reducing oxygen and blood supply to the fetus.

- Women who smoke have a greater risk of having a preterm infant.

- The risk of stillbirth and infant death during the first week of life is greater among those women who smoke than for nonsmoking women.

- The risk of an infant developing sudden infant death (SIDS) is greater for infants of women who smoked during pregnancy (Fotheringham, et al., 1983) and (Finnegan, 1985).

B. Alcohol

. Alcoholism and the adverse effects of alcohol on the fetus are continuing public health issues. Alcohol use is also associated with poor nutrition, smoking, and use of other drugs, as well as, emotional stress and lack of regular medical care; all of which serve to create and exacerbate prenatal high-risk conditions.

. Alcohol related birth defects are as follows:

1. Fetal Alcohol Syndrome (FAS): Infants born with FAS are usually small, with small head circumference. However, unlike "small" newborns these infants never "catch-up" to their unaffected peers. They also have central nervous system problems including mental retardation (average IQ of 60), poor motor development, hyperactivity, and decreased attention span. They have facial characteristics which include small, flat nose, thin upper lip, narrow, widely spaced eyes, a protruding forehead, receding chin, and deformed ears. Other abnormalities can include altered palm crease patterns and congenital heart defects.

2. Fetal Alcohol Effects (FAE): These are in infants who have one or two of the above characteristics. Therefore, since FAE is not as pronounced as FAS, FAE is more difficult to diagnose, especially if the mother's alcohol consumption history is unknown (Hoyme, 1990), (Rosett, et al.), and (Poe, 1982).

C. Prescription Drugs

1. Lithium: A drug used to treat manic-depressive disorder which can result in congenital heart defects.

2. Dilantin: A drug used to control seizures that is associated with the fetal hydantoin syndrome (FHS). Features of FHS include prenatal onset growth deficiency, mild to moderate mental retardation, and abnormal facial characteristics.

3. Valium: A drug used as a muscle relaxant that is often used to relieve anxiety. Cleft lip and palate have been reported in infants of

mothers who used the drug during their first trimester of pregnancy. Infants born to mothers who used valium during later stages of pregnancy have shown symptoms of respiratory distress, weak skeletal muscles, and exaggerated reflexes. These symptoms have been reported to last from 16 days to one year after delivery.

4. There are other prescription drugs which cause developmental disabilities and many which do not cause developmental disabilities. The above list is a list of the ones most frequently used. The use of any prescription should be discussed with the doctor when receiving prenatal care (Hoyme, 1990) and (Fotheringham, et al., 1983).

D. Over-The-Counter Drugs

1. Aspirin: Aspirin is one of the most commonly used non-prescription drugs. The relationship between aspirin taken during pregnancy and fetal damage is not yet clear. However, studies have documented many hazards. Large doses of aspirin taken during pregnancy are associated with low birth weights, stillbirths, and neonatal deaths. It has also been found that the length of pregnancy and labor can be prolonged and the incidence of antepartum and postpartum bleeding, as well as other complications of delivery are higher.

2. There are other over-the-counter drugs which cause developmental disabilities and many which do not cause developmental disabilities. Over-the-counter drugs should be used sparingly and discussed with the doctor when receiving prenatal care (Fotheringham, et al., 1983).

E. Caffeine

. A stimulant found in coffee, tea, colas and other soft drinks, cocoa, chocolate, and certain prescription and non-prescription drugs. Caffeine is known to cross the placenta, thereby affecting the fetus in much the same way as it does adults. It reduces the blood flow to the brain.

. It is recommended that caffeine intake be discussed with and monitored by the pregnant woman's doctor during prenatal care (Poe, 1982) and (Fotheringham, et al., 1983).

F. Illegal Drugs

1. Heroin: Heroin use in pregnant women can result in still-births, fetal growth retardation, low birth weight, and prematurity. Heroin addicts tend to be in poor health generally. They tend to be IV drug users which puts them at risk of HIV infection. They are not likely to seek or receive prenatal care. Consequently heroin-addicted women are at increased risk for complications during pregnancy.

   Withdrawal symptoms in infants born to dependent mothers are common, appearing anytime from birth to four days after. They include nervous system irritability, gastrointestinal and respiratory disorders, vomiting, a high, shrill cry, fever, sweating, diarrhea, and sometimes convulsions. These symptoms do, however, subside rapidly with treatment.

   Methadone is used in the treatment of heroin. It is also addictive. It is dispensed at clinics and a pregnant woman is more likely to receive prenatal care if she is on methadone rather than heroin. There are some complications associated with the use of methadone although they are not as great as the ones associated with the use of heroin.

2. Marijuana: The affects of marijuana on the fetus are not clear. There are, however, a number of compounds within this drug that are potentially dangerous to the fetus. Marijuana use can result in fetal growth retardation and low birth weight. It can cause later developmental problems. Smoking marijuana can increase the risk of fetal or infant death.

3. Cocaine: Cocaine use among pregnant women can result in preterm labor and low birth weight, neurological problems, small head circumference, and cardiorespiratory complications.

   Withdrawal symptoms in infants include difficulty with sleeping, with staying awake, and/or crying.

   Cocaine addicts tend to be in poor health in general. They tend to be IV drug users which puts them at risk of HIV infection. They are not always likely to seek or receive prenatal care.

   Much research is being conducted regarding the effects of cocaine on infants at this time.

Crack is cocaine in smokeable form.

4. There are other illegal drugs which cause developmental disabilities. The above is a list of some of the ones most frequently used. The complicating factor with illegal drug use is that often the women are poly drug users. This means they use more than one illegal drug and often use tobacco and alcohol as well (Fotheringham, et al., 1983), (Evrad and Scola, 1990), and (The American Council for Drug Education, 1991).

II. Prevention Strategies

- Prevention of developmental disabilities from tobacco, alcohol, and drugs is simple but often difficult. A woman planning a pregnancy should stop use of tobacco, alcohol, and illegal drugs before pregnancy and abstain from use during the entire pregnancy. If the pregnancy is unplanned, the woman should stop use of these as soon as she finds out she is pregnant and abstain from use during the entire pregnancy. This is frequently difficult for even a casual user but for a woman who has problems with alcohol and drugs or is addicted, this is very difficult.

- For a pregnant woman addicted to alcohol and/or drugs (and frequently the woman is a polyuser and therefore addicted to both), substance abuse treatment (in-patient, out-patient, or both) and involvement with Alcoholics/Narcotics Anonymous are crucial.

- A pregnant woman should consult with her doctor during prenatal care on the use of over-the-counter drugs, prescription drugs, and caffeine.

- The sooner in pregnancy a woman stops using tobacco, alcohol, and drugs the better. The first two trimesters of pregnancy are critical since that is when the organs and other body parts are developing. If damage has been done to the fetus it cannot be corrected, but no additional damage will occur (Finnegan, 1985), (Rosett, et al.), and (The American Council for Drug Education, 1991).

III. References and Resources

A. References Used

Evrad, John R. and Scola, Patricia S. (1990). Preparation for Parenthood. In Siegfried M. Pueschel and James A. Mulick (eds.), Prevention of

Developmental Disabilities. Baltimore: Paul H. Brookes Publishing Company.

Finnegan, Loretta P. (1985). Smoking and Its Effect on Pregnancy and the Newborn. In Shaul Harel and Nicholas J. Anastasiow (eds.), The At-Risk Infant: Psycho/Socio/Medical Aspects. Baltimore: Paul H. Brookes Publishing Company.

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Rosett, Henry L.; Weiner, Lyn; Morse, Barbara A. (no date). Identification and Prevention of Fetal Alcohol Syndrome. Brookline, Massachusetts: Boston University School of Medicine.

The American Council for Drug Education. (1991). Drugs and Pregnancy - It's Not Worth the Risk. Rockville: Author.

B. Resources

Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services

Virginia Department of Health

Virginia Department of Social Services

Virginia Department of Education

Regional Perinatal Centers

- Medical College of Virginia, Virginia Commonwealth University in Richmond
- University of Virginia in Charlottesville

Fairfax Hospital in Falls Church
Virginia Baptist Hospital in Lynchburg
Roanoke Memorial Hospital in Roanoke
Children's Hospital of the King's Daughters and Sentara Norfolk General in Norfolk

Center for Perinatal Addiction, Virginia Commonwealth University

Project LINK under Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services

March of Dimes

National Association for Perinatal Addiction Research and Education
312-329-2512

Alcoholics Anonymous/Narcotics Anonymous

C. Other References and Resources (complete with your own)

Sever, John L. and Brent, Robert L. (eds.). (1986). Teratogen Update: Environmentally Induced Birth Defect Risks. New York: Alan R. Liss, Inc.

Whitley, Elizabeth B. (ed.) (1991). Monograph on A Substance Abuse Colloquium. Richmond: Virginia Institute for Developmental Disabilities.

Environmental Exposures

I. Problem and Prevention Strategies

There are environmental substances which can cause developmental disabilities if the pregnant woman is exposed to them. Three of these are as follows:

A. Radiation

1. Description

. Studies indicate that radiation in large doses (greater than 10 rads) are likely to be damaging to the fetus. However, diagnostic X-rays usually produce 500 millirads (1000 millirads = 1 rad) or less, and therefore are not considered to deliver damaging effects to the fetus. Large doses of radiation which were delivered during the atomic blasts in Hiroshima and Nagasaki were associated with increased fetal loss, small head circumference, and mental retardation in those surviving infants. Results such as these might result from large therapeutic doses of radiation such as that used to treat cancer (Hoyme, 1990).

2. Prevention Strategies

. Women who suspect they may be pregnant, or who are pregnant should notify their doctor or X-ray technician prior to exposure to radiation. This includes dental x-rays which are done on a regular basis. Decisions can then be made about exposure to radiation (Fotheringham, et al., 1983).

B. Methyl Mercury Poisoning

1. Description

. Mercury is discharged into the environment as industrial waste and converted into methyl mercury. Rivers typically then become polluted and fish become polluted. When a pregnant woman ingests fish contaminated with methyl mercury the fetus or embryo can be affected. The resulting effects are severe neurologic dysfunction with mental retardation, small head circumference, spasticity, and behavioral problems. Cerebral palsy appears to be the major feature.

- Ingesting this substance after birth appears to have no effect on the developing child's central nervous system. It is only during the embryonic or fetal periods that central nervous system damage occurs (Hoyme, 1990) and (Fotheringham, et al., 1983).

2. Prevention Strategies

- Pregnant women should be advised of this type of poisoning particularly in areas where there is a lot of industry and where fish is a major component of a woman's regular diet (Fotheringham, et al., 1983).

C. Lead

1. Description

- Lead is a lethal poison which can cause death, mental retardation, and other serious disabilities. Lead can be found in lead-based paint and in chips and dust resulting from stripping paint, in leaded automobile gasoline and automobile exhaust fumes, in food which has been in containers made of lead or painted with lead-based paint, in water which came through lead pipes, etc.

- Lead can enter the body through the skin, the respiratory track and gastrointestinal track.

- Lead is stored in the bone and can be released in the body at a rapid rate during pregnancy.

- Lead that enters the pregnant woman's body and is stored in the body can cause death and disabilities in the fetus.

- Lead also can cause death and disability to infants and children exposed to it. In fact, lead poisoning until recently was thought to only be a childhood problem (Silbergeld, 1990) and (Senft and Pueschel, 1990).

2. Prevention Strategies

- Pregnant women can be tested for their blood lead level as well as their bone lead level. Research is underway on the

usefulness of this and possible management of this.

- Pregnant women should avoid sources of lead whenever possible. This is particularly important for women living in older houses which were painted with lead-based paint and particularly in these houses which are being or have been renovated (Silbergeld, 1990) and (Senft and Pueschel, 1990).

II. References and Resources

A. References Used

Fotheringham, John B.; Hambley, Walter D.; Haddad-Curran, Harriett W. (1983). Prevention of Intellectual Handicaps. Toronto: The Martin Group.

Hoyme, H. Eugene. (1990). Teratogenic Causes of Developmental Disabilities. In Siegfried M. Pueschel and James A. Mulick (eds.), Prevention of Developmental Disabilities. Baltimore: Paul H. Brookes Publishing Company.

Senft, Karen E. and Pueschel, Siegfried. (1990). Lead Poisoning in Childhood. In Siegfried M. Pueschel and James A. Mulick (eds.), Prevention of Developmental Disabilities. Baltimore: Paul H. Brookes Publishing Company.

Silbergeld, Ellen K. Implications of New Data on Lead Toxicity for Managing and Preventing Exposure. Environmental Health Perspective. Vol. 89. 49-54, 1990.

B. Resources

Virginia Department of Health

Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services

Regional Perinatal Centers

Medical College of Virginia, Virginia Commonwealth University in Richmond
University of Virginia in Charlottesville
Fairfax Hospital in Falls Church

Virginia Baptist Hospital in Lynchburg
Roanoke Memorial Hospital in Roanoke
Children's Hospital of the King's Daughters and Sentara Norfolk General in Norfolk

C. Other References and Resources (complete with your own)

Sever, John L. and Brent, Robert L. (eds). (1986). Teratogen Update: Environmentally Induced Birth Defect Risks. New York: Alan R. Liss, Inc.

Maternal Age

I. Problem and Prevention Strategies

There are problems associated in pregnancy for the younger (adolescent) woman and for the woman who is 35 and over.

A. Adolescent Pregnant Women

1. Description

- A disconcerting fact is that the younger the age at which the first sexual experience occurs, the less likely it is that the individual will use some form of contraception. Many females between the ages of 15 and 19 do not use a contraceptive at the time of their first sexual intercourse. Unwanted pregnancies often occur within six months of the first sexual intercourse. Finally, many sexually active teens do not use contraceptives on a regular basis. Therefore, in spite of the availability of contraceptives, it appears that their use remains inconsistent by adolescents.

- Other issues related to the social consequences of adolescent pregnancy include: most adolescents choose to keep the baby; most mothers are age 17 and below and drop out of high school; and many teenage marriages result in pregnancy and divorce within five years.

- Many of the health risks associated with teen pregnancy stem from the physical and emotional immaturity of the teenager. The continuing growth of the teen places heavy demands on the adolescent body. The developing fetus also places heavy demands on the body. Adolescence is a time in life when nutritional needs are the greatest. Pregnancy under optimal circumstances is also a time when good nutrition is exceedingly important. Many teens have poor eating habits and are not likely to get the rest they need.

- Pregnant teens tend to seek prenatal care late in their pregnancy, if at all, and thereby increase the risk for poor pregnancy outcome. Teens may delay seeking prenatal care for a variety of reasons such as: denial, fear of parental reaction, shame, and ignorance regarding pregnancy or available services. Complications can include miscarriage,

hemorrhage, and/or toxemia. The death rate from complications of pregnancy and childbirth rises as the age of the teen mother decreases.

- Teenagers who give birth are in fact children having children.

- Teen pregnancy often results in miscarriages, premature births, and low birth weight. Low birth weight can cause many problems for the infant.

- In discussing adolescent pregnancy, the distinction needs to be made between 18 and 19 year old adolescents who are apt to be more responsible, mature, and more ready for parenthood than those below 18 years of age.

- The older adolescents are more likely to seek prenatal care and social support systems. Those in the younger groups are more likely to experience health and social problems during this time (Evard and Scola, 1990), (Fotheringham, et al., 1983), and (Poe, 1982).

2. Prevention Strategies

- Prevention of disabilities associated with adolescent pregnancy takes two forms:
  1. Providing strategies that prevent unwanted pregnancy in this population, and
  2. Outreach to pregnant adolescents to provide them avenues of prenatal care and social support.

- Discouraging Pregnancy in Adolescents:

  - Adolescent sexual activity is often spontaneous and much of the literature indicates that many adolescents do not use contraceptives.

  - Adolescent pregnancy prevention programs fall into three groups:
    1. those that seek to delay/reduce sexual activity,
    2. those that stress the use of contraceptives among sexually active teenagers, and
    3. those that provide meaningful alternatives to pregnancy and childbearing.

- Two types of programs seek to delay/reduce sexual activity among adolescents. These are traditional sex education and assertiveness/life skill-training approaches such as communication skills, goal setting, coping and refusal skills, etc. These two programs are often used together.

- Programs that stress the use of contraceptives among sexually active adolescents are assertiveness/skills approach, sex education, family planning services, school-based programs, and community-based multipurpose youth centers.

- Programs that provide meaningful alternatives to pregnancy and childbearing deal with education and jobs.

- Family Life Education is now mandated by Virginia law in the public schools in Virginia (Fotheringham, et al., 1983) and (Galano, 1990).

- Intervention with Pregnant Adolescents:

  - The following are proposed interventions for those adolescents who do become pregnant:
    1. Comprehensive outreach programs are needed to ensure that those infants born are the healthiest babies possible.
    2. High quality, consistent prenatal care can greatly reduce the risks of neurological disorders (such as learning disabilities or mental retardation) in infants of adolescent mothers.
    3. Comprehensive psychosocial health counseling and support can increase the likelihood that the young woman may complete her high school education, seek assistance with parenting skills, be less likely to conceive again during her adolescent years, and be more likely to use the support services available to her (Fotheringham, et al., 1983).

B. Older Pregnant Women

1. Description

. Maternal age at 35 or greater can have poor pregnancy outcomes such as perinatal death, stillborn, low birth weight, and neurological abnormalities. Older paternal age can also be a factor in infants born with disabilities.

. Maternal age of 35 years or greater is the primary indication for one to seek prenatal genetic counseling. After a woman reaches 35 years of age, the risk of chromosome abnormalities and therefore a child born with birth disorders such as Down syndrome doubles every 2.5 years. Paternal age effects has been identified, but to a markedly lesser degree (Miller, 1990) and (Fotheringham, et al. 1983).

2. Preventative Strategies

. Education of the public as to the optimal childbearing age.

. Prenatal amniocentesis and other indicated diagnostic techniques.

. Early, accessible, affordable high quality prenatal care should be made available (Fotheringham, et al., 1983) and (Miller, 1990).

II. References and Resources

A. References Used

Evard, John R., and Scola, Patricia S. (1990). Preparation for Parenthood. In Siegfried M. Pueschel and James A. Mulick (eds.), Prevention of Developmental Disabilities. Baltimore: Paul H. Brookes Publishing Company.

Fotheringham, John B.; Hambley, Walter D.; Haddad-Curran, Harriet W. (1983). Prevention of Intellectual Handicaps. Toronto: The Martin Group.

Galano, Joseph. (1990). Adolescent Pregnancy Prevention: Building Better Programs and Evaluating Their Impacts. Richmond: Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services.

Miller, Wayne A. (1990). Prenatal Genetic Diagnosis. In Siegfried M. Pueschel and James A. Mulick (eds.), Prevention of Developmental Disabilities. Baltimore: Paul H. Brookes Publishing Company.

Poe, Elisabeth S. (1982). Prevention of Mental Retardation - A Manual for Community Program Development. Charlottesville: Region Ten Community Services Board.

B. Resources

Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services

Virginia Department of Health

Virginia Department of Education

Virginia Department of Social Services

Genetics programs at:
- Medical College of Virginia, Virginia Commonwealth University in Richmond
- University of Virginia in Charlottesville
- Genetics and IVF Institute in Fairfax
- Medical College of Hampton Roads in Norfolk

Better Beginnings Program under Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services

C. Other References and Resources (complete with your own)

Preterm Labor

I. Problem

- Preterm labor and delivery (delivery prior to 37 weeks) can lead to neurologic handicaps and deliveries at less than 30 weeks can lead to developmental disabilities such as cerebral palsy. The infants are obviously low birth weight.

- There are a number of causes of preterm labor and delivery including a multiple pregnancy (twins), a woman who has delivered one or more premature infants, placental insufficiency, bleeding, congenital anomalies, premature rupture of the membranes, stress and fatigue, low progesterone levels, etc. (Cetrulo, et al., 1990).

II. Prevention Strategies

- Education of all pregnant women as to proper care for themselves and detection for preterm labor.

- Identification of woman at risk using predictive criteria.

- Regular prenatal visits with visit frequency based on identified risks.

- Possible drug therapy for preterm labor.

- Possible bed rest, increased fluid hydration, and uterine activity monitoring for preterm labor.

- Possible use of a prenatal center for perterm delivery (Cetrulo, 1990).

III. References and Resources

A. References Used

Cetrulo, Curtis L.; D'Alton, Mary E.; Newton, Edward R. (1990). Etiology of Preterm Labor. In Siegfried M. Pueschel and James A. Mulick (eds.), Prevention of Developmental Disabilities. Baltimore: Paul H. Brookes Publishing Company.

B. Resources

Virginia Department of Health

Regional Perinatal Centers

Medical College of Virginia at Virginia Commonwealth University in Richmond
University of Virginia in Charlottesville
Fairfax Hospital in Lynchburg
Virginia Baptist Hospital in Lynchburg
Roanoke Memorial Hospital in Roanoke
Children's Hospital of the King's Daughters and Sentara Norfolk General in Norfolk

Virginia Perinatal Association

C. Other References and Resources (complete with your own)

Ansari, A. and Reynolds, R. Cervical Incompetence. Journal of Reproductive Medicine. 32:3, 1987.

Creasy, R. (1984). Preterm Labor and Delivery: Disorders of Partuition. In R. Creasy and R. Resnike (eds.), Maternal Fetal Medicine. Philadelphia: W. B. Sanders and Company.

Creasy, R. and Herron, M. Prevention of Preterm Birth. Seminars in Perinatology 5(3): 295, 1984.

Morrison, J. C. A Puzzel Worth Solving. Obstetrics and Gynecology, 76:55-12S, 1990.

Newman, R.; Gill, P.; and Katz, M. Maternal Perception of Uterine Activity. Obstetrics and Gynecology 68(6): 756, 1986.

Stubblefield, P. (1984). Causes and Prevention of Preterm Birth: An Overview. In F. Fuchs and P. Stubblefield (eds.), Preterm Birth. New York: MacMillan Publishing Company.

PRIMARY PREVENTION OF DEVELOPMENTAL DISABILITIES

INFANCY/CHILDHOOD/ADOLESCENCE

Overview

Ideally, at this point, there is a good pregnancy outcome and a healthy baby is born. However, going back to the definition of developmental disability, the disability is one that manifests before the person attains the age of 22. Therefore, primary prevention strategies are needed during infancy, childhood, and adolescence to assist the child in becoming a healthy adult.

There are infants that are born at high risk of developing developmental disabilities. These infants should be screened at birth and throughout the first year of life and monitored as necessary. High risk infants include but are not limited to:

1. those cared for in neonatal intensive care units,
2. those born preterm or delivered at less than 37 weeks gestation,
3. those with low birth weights or weighing less than 2,500 grams at birth,
4. those with asphyxia: 5 minute Apgar Score less than 3,
5. those with serious medical problems,
6. those whose mothers abused alcohol and drugs during pregnancy,
7. those whose mothers had inadequate prenatal care,
8. those born to mothers under 18 years of age or over 35 years of age,
9. those whose mothers have psychiatric disorders, and
10. those born to dysfunctional families.

All children, but particularly the ones at high risk, should be screened on a regular basis during childhood.

If problems/conditions are detected, the infants and children (zero to two) should be referred for a comprehensive assessment and based on findings referred to early intervention programs. These programs are designed to work with infants, children, and their families to correct problems/conditions if possible, and if not, to prevent them from becoming more serious. Children over two should also be referred for a comprehensive assessment and based on findings reported for appropriate services/programs.

Virginia law requires all infants to be screened at birth for metabolic disorders (phenylketonuria, congenital hypothyroidism, homocystinuria, maple sugar urine disease, galactosemia, sickle cell anemia, and biotinidase deficiency) and treated if necessary; infants should also be screened at birth for other conditions such as hyperbilirubinemia; infants and children should be immunized against infectious diseases as required by Virginia law; and infants, children, and adolescents should be checked on a regular basis for other diseases/disorders/conditions and treated if necessary.

It is important for infants, children, and adolescents to have proper nutrition; to avoid harmful environmental exposures; to avoid alcohol and drugs; to avoid unintentional injuries; and to be protected from child abuse and neglect.

The above infancy/childhood/adolescence strategies should prevent problems from occuring and, if not, detect problems early so that they can be treated if necessary. They should assist the child to grow into a healthy adult.

Metabolic Disorders

I. Problem and Prevention Strategies

Inborn errors of metabolism and other genetic disorders can be identified through simple and inexpensive screening tests done the first few days of a newborn infant's life. All newborn infants in Virginia are screened for the following disorders:

A. Phenylketonuria (PKU)

1. Description

- A lack of an enzyme (phenylalanine hydroxylase) needed to metabolize proteins containing the amino acid, phenylalanine.

- It can cause convulsions and severe mental retardation (Action for Prevention, 1989) and (Levy, 1990).

2. Prevention Strategies

- Disabilities are preventable by early screening and detection foilowed with appropriate medical management which includes dietary management and frequent developmental assessments.

- Women of child-bearing age who have PKU should resume the diet prior to conception to prevent a fetal death or the birth of a child with disabilities (Action for Prevention, 1989) and (Levy, 1990).

B. Congenital Hypothyroidism

1. Description

- A deficiency of a thyroid hormone which can cause poor feedings, constipation, and in severe cases, stunted physical and mental growth (Action for Prevention, 1989) and (Levy, 1990).

2. Prevention Strategies

. Disabilities are preventable by early screening, detection, and treatment with thyroid hormone (Action for Prevention, 1989) and (Levy, 1990).

C. Homocystinuria

1. Description

. A deficiency of enzyme (cystationine synthetase) which causes psychomotor retardation, cataracts, seizures, mental retardation, and muscle weakness (Action for Prevention, 1989) and (Levy, 1990).

2. Prevention Strategies

. Early screening and detection, appropriate medical management by a metabolic specialist, and diet control consisting of low methionine, cystine supplemented diet prevents disabilities (Action for Prevention, 1989) and (Levy, 1990).

D. Maple Syrup Urine Disease (MSUD)

1. Description

. An enzyme (keto acid decarboxylase) deficiency that causes feeding difficulties, developmental retardation, seizures, mental retardation, acute acidosis, and death (Action for Prevention, 1989) and (Levy, 1990).

2. Prevention Strategies

. Early screening and detection, appropriate medical management by a metabolic specialist, and special infant formula (low leucine, isoleucine, and valine) is relatively effective for prevention of disabilities (Action for Prevention, 1989) and (Levy, 1990).

E. Galactosemia

1. Description

. An inborn error of carbohydrate metabolism with initial symptoms evident when fed milk containing lactose.

. It causes liver and renal dysfunction, cataracts, and mental retardation (Action for Prevention, 1989) and (Levy, 1990).

2. Prevention Strategies

. Early screening and detection, appropriate medical management by a metabolic specialist, and dietary management which includes exclusion of the lactose found in milk and other lactose containing foods is somewhat effective in preventing disabilities and does prevent death (Action for Prevention, 1989) and (Levy, 1990).

F. Sickle Cell Anemia (Disease)

1. Description

. An abnormality which causes red blood cells to become sickle shaped and lose their elasticity causing severe anemia, clogging of capillaries, and spleen problems.

. If undiagnosed and untreated with prophylactic penicillin, death results in approximately 30 percent during the first two years of life due to susceptibility to severe bacterial infections (Action for Prevention, 1989).

2. Prevention Strategies

. Prenatal screening and newborn screening is possible. This disease occurs almost exclusively in Afro-Americans. Early treatment with prophylactic penicillin is essential and medical management by a pediatric

hemotologist (Action for Prevention, 1989).

G. Biotinidase Deficiency

1. Description

. The body fails to produce a chemical called biotinidase.

. It can cause mental retardation and other disabilities.

2. Prevention Strategies

. Early screening and detection, appropriate medical management, and treatment with a vitamin biotin prevents disabilities.

Virginia law requires that all seven disorders be screened for in newborn infants and appropriate and prompt follow-up be done. The Department of General Services, Division of Consolidated Services performs the screenings and reports abnormal results to the Virginia Department of Health, Division of Maternal and Child Health for follow-up.

II. References and Resources

A. References Used

Action for Prevention, Inc. (1989). The Virginia Agenda for Prevention of Developmental Disabilities in the 1990's: A Resource Document. Richmond: Virginia Institute for Developmental Disabilities.

Levy, Harry L. (1990). Neonatal Screening for Metabolic Disorders. In Siegfried M. Pueschel and James A. Mulick (eds.), Prevention of Developmental Disabilities. Baltimore: Paul H. Brookes Publishing Company.

B. Resources

Virginia Department of Health

Virginia Department of Mental Health, Mental Retardation, and

Substance Abuse Services

Regional Perinatal Centers

Medical College of Virginia, Virginia Commonwealth University in Richmond
University of Virginia in Charlottesville
Virginia Baptist Hospital in Lynchburg
Roanoke Memorial Hospital in Roanoke
Fairfax Hospital in Falls Church
Children's Hospital of the King's Daughters and Sentara Norfolk General in Norfolk

Medical College of Virginia, Virginia Commonwealth University, Department of Pediatrics

University of Virginia, Department of Pediatrics

C. Other References and Resources (complete with your own)

Miller, C. Arden; Fine, Amy; Adkins-Taylor, Sharon (1989). Monitoring Children's Health: Key Indicators. Washington, D.C.: American Public Health Association.

Other Conditions

I. Problem

There are other conditions besides metabolic disorders in infants and children which can cause developmental disabilities. One of the more common ones is hyperbilirubinemia.

- Bilirubin is an organic compound derived from the breakdown of the red blood cells.

- Excessive amounts of bilirubin (hyperbilirubinemia) can be toxic to the central nervous system causing long-term neurologic disabilities and occasionally mental retardation.

- Conditions which can result from the central nervous system and particularly the brain being exposed to elevated amounts of bilirubin are:
  1. diminished IQ,
  2. diminished motor dysfunction, and
  3. psychomotor delay.

- The RH disease was previously the main cause of excessive amounts of bilirubin. This disease is now often prevented. Elevated amounts of bilirubin are also associated with infants of low birth weight and preterm birth, and larger infants with asplyxia, sepsis, and/or severe respiratory distress (Cashore, 1990).

II. Prevention Strategies

- Women with the RH factor should be monitored during pregnancy.

- Infants should be tested at birth for excessive amount of bilirubin.

- With elevated amounts of bilirubin, the infant should be treated with phototherapy. With more excessive amounts of bilirubin, the infant should have a whole blood exchange transfusion (Cashore, 1990).

III. References and Resources

A. References Used

Cashore, William J. (1990). Contribution of Hyperbilirubinemia To Developmental Disabilties. In Siegfried M. Pueschel and James M. Mulick (eds.), Prevention of Developmental Disabilities. Baltimore: Paul H. Brookes Publishing Company.

B. Resources

Virginia Department of Health

Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services

Regional Perinatal Centers

Medical College of Virginia, Virginia Commonwealth University in Richmond
University of Virginia in Charlottesville
Virginia Baptist Hospital in Lynchburg
Roanoke Memorial Hospital in Roanoke
Fairfax Hospital in Falls Church
Children's Hospital of the King's Daughters and Sentara Norfolk General in Norfolk

C. Other References and Resources (complete with your own)

Infectious Diseases

I. Problem and Prevention Strategies

There are a number of infectious diseases that if contracted during infancy and childhood can cause developmental disabilities. Some of them are as follows:

A. Septic or Acute Bacterial Meningitis

1. Description

. Infection of the meninges (the lining that covers the brain). There is acute onset and temperature elevation. Even when treated, this infection can cause brain damage. The earlier that treatment is sought, the more promising the outlook.

. Those at highest risk are male children living in lower socio-economic conditions in more densely populated areas. The hemophilus influenza is the most common cause of meningitis in children, usually occurring between the ages of three months and three years.

. Neonatal Meningitis

. Occurs within the first month of life.

. Two types of Group B streptococcus cause meningitis. One occurs within the first few days of life and carries with it a high death rate. It is related to obstetrical problems such as maternal infections, prolonged rupture of the membranes, complications during labor and delivery, and low birth weight.

. The second pattern appears after the first week of life and carries a lower death rate but a high rate of neurologic damage to the survivors. Infants exhibit mental or motor disabilities, convulsive disorders, hydrocephalus, hearing loss, or abnormal speech patterns. Even with prompt treatment, the effects of neonatal meningitis can be serious.

. Other organisms can cause neonatal meningitis.

. Childhood Meningitis

- Meningitis during the first year of life can lead to a variety of disabling conditions. The type and severity of the disability depends upon the organism involved, the age of the child, and the promptness of the treatment.

- A variety of disabilities have been reported in connection with childhood meningitis. These are reduced intelligence, mental retardation, cerebral palsy, speech, hearing and vision disorders, and behavior problems (Fotheringham, et al., 1983).

2. Prevention Strategies

- Infants born to a woman with acute infectious, prolonged membrane rupture, and/or complications during labor and delivery, as well as those born premature and low birth weight are at high risk and should be monitored and treated if necessary with antibiotics.

- Immunization is available to young children to prevent meningitis. This is particularly important for children who have conditions such as sickle cell anemia, cystic fibrosis, etc. (Fotheringham, et al. 1983).

B. Encephalitis

1. Description

- This is a progressive inflammation of the brain, often resulting in damage to different parts of the brain, which may or may not be long-lasting.

- A variety of organisms cause this infection including bacteria, fungi, and viruses.

- The viruses that produce influenza, mumps, chicken pox, herpes simplex, rubella, and measles (rubeola) can all lead to encephalitis (Fotheringham, et al., 1983).

2. Prevention Strategies

. The best strategy for prevention is immunization for conditions which vaccines are currently available. In addition, prompt identification and treatment is important. (Fotheringham, et al., 1983).

C. Others

1. Description

. There are a number of other infectious diseases which can cause developmental disabilities. These have been reduced greatly over the years due to immunizations. These are diphtheria, measles, mumps, pertussis (whooping cough), poliomyelitis (polio), and tetanus. The following table lists those infectious diseases and the developmental disabilities caused by them (Hinman, 1990):

Table 2 Developmental disabilities associated with postnatally acquired vaccine-preventable diseases

Infectious Disease	Developmental Disability
Diphtheria	Death Myocarditis Paralysis Oscular paralysis
Measles	Death Blindness Deafness Encephalitis Mental retardation Subacute sclerosing panencephalitis
Mumps	Deafness
Whooping Cough	Death Brain damage Bronchiectasis/emphysema
Polio	Death Paralysis
Rubella	Encephalitis
Tetanus	Death

2. Prevention Strategies

. These diseases can be prevented by adequate immunizations recommended by the American Academy of Pediatrics.

. Virginia law requires immunizations for the above diseases before a child enters school. Immunizations are usually given to young children routinely in well baby care (Hinman, 1990) and (Action for Prevention, 1989).

II. References and Resources

A. References Used

Action for Prevention, Inc. (1989). The Virginia Agenda for Prevention of Developmental Disabilities in the 1990's: A Resource Document. Richmond: Virginia Institute for Developmental Disabilities.

Fotheringham, John B.; Hambley, Walter D.; Haddad-Curran, Harriet W. (1983). Prevention of Intellectual Handicaps. Toronto: The Martin Group.

Hinman, Alan R. (1990). Immunoprophylaxis of Developmental Disabilities. In Siegfried M. Pueschel and James A. Mulick (eds.), Prevention of Developmental Disabilities. Baltimore: Paul H. Brookes Publishing Company.

B. Resources

Virginia Department of Health

Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services

Virginia Department of Education

American Academy of Pediatrics

C. Other References and Resources (complete with your own)

Sever, John L. and Brent, Robert L. (eds). (1986). Teratogen Update: Environmentally Induced Birth Defect Risks. New York: Alan R. Liss, Inc.

Nutrition

I. Problem

- Proper and adequate nutrition is essential during infancy/childhood/adolescence. From birth through adolescence, the body is constantly changing and growing.

- Poor nutrition/malnutrition can come from poor eating habits, child abuse and/or neglect, and diseases/conditions (inborn errors of metabolism previously discussed, diabetes, etc.). Poor nutrition contributes to poor health in general.

- Poor nutrition/malnutrition can lead to an infant/child/adolescent not growing adequately physically. Poorly/under developed muscles and bones cause numerous physical disabilities. Poorly/under developed organs (including the brain) can also cause numerous physical disabilities. In addition, a poorly/under developed brain can cause mental disabilities including mental retardation (Fotheringham, et al., 1983) and (Morgan, 1990).

II. Prevention Strategies

- Prevention of poor nutrition/malnutrition begins with parents becoming familiar with/being taught nutritional requirements of infants/children/adolescents and taking responsibility for ensuring adequate nutrition of their child.

- Well baby care is important to monitor proper and adequate nutrition and identify and treat conditions which might interfere with nutrition.

- Well baby care is important when an infant is being breast fed to ensure the baby is receiving proper nutrition. There are many possible benefits to infants being breast fed.

- Parents might also need assistance in providing their children food and this can be done through the WIC program, food stamps, the USDA school lunch program, etc.

- Prevention continues with children and adolescents becoming familiar with healthy eating habits and encouraged to develop and follow them. Nutrition is taught in the Health curriculum in Virginia Public Schools (Fotheringham, et al., 1983), (Morgan, 1990), and (Poe, 1982).

III. References and Resources

A. References Used

Fotheringham, John B.; Hambley, Walter D.; Haddad-Curran, Harriet W. (1983). Prevention of Intellectual Handicaps. Toronto: The Martin Group.

Morgan, Brian L. G. (1990). Nutrition and Brain Development. In Siegfried M. Pueschel and James A. Mulick (eds.), Prevention of Developmental Disabilities. Baltimore: Paul H. Brookes Publishing Company.

Poe, Elisabeth S. (1982). Prevention of Mental Retardation - A Manual for Community Program Development. Charlottesville: Region Ten Community Services Board.

B. Resources

Virginia Department of Health

Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services

Virginia Department of Education

Virginia Cooperative Extension Services

WIC Program (Supplemental Food Program for Women, Infants, and Children) under Virginia Department of Health

Food Stamp Program under Virginia Department of Social Services

USDA School Lunch Program under Virginia Department of Education

C. Other References and Resources (complete with your own)

Alcohol and Drug Use

I. Problem and Prevention Strategies

A. Children Of Parents Who Use/Abuse Alcohol and Drugs

1. Description

- Parents who abuse alcohol and drugs put their children at risk of developing physical and/or mental disabilities.

- Alcoholism is a chronic, progressive, and fatal disease which can prevent a parent from properly caring for a child, due to dysfunctioning and/or financial problems, lead to accidents particularly automobile accidents which can involve the child, and lead to family dysfunction/family violence/family dissolvement.

- Addiction to drugs can cause the same things as alcoholism plus introduce criminal activity which further puts the child at risk.

- Children of alcoholics/drug addicts are three to four times more likely to become alcoholics/drug addicts themselves than other children.

- At least 10 percent of the population is addicted to alcohol and/or drugs. This is a very conservative estimate (Kinney, 1987) and (Monaco, 1991).

2. Prevention Strategies

- Assist parents to obtain early treatment for alcoholism and drug addiction. Treatment can be in-patient or out-patient. It should also involve attending Alcoholics/Narcotics Anonymous.

- Efforts should continue to be made to get the addicted parent and all other significant family members in treatment and involved with support groups such as Al-Anon.

- Early effort should be made with children of alcoholics/drug addicts to prevent them from becoming alcoholics/drug addicts. There are special groups for this (Kinney, 1987),

(Mannelo, 1991), and (Monaco, 1991).

B. Children/Adolescents Who Use/Abuse Alcohol and Drugs

1. Description

- Part of a child growing up often involves risk taking behaviors such as experimentation with alcohol and drugs. This is particularly likely during adolescence. Peer pressure is strong on using alcohol and drugs. This is problematic for a number of reasons.

- Being under the influence of alcohol and drugs inhibits normal judgment and decision making and makes many accidents more likely - particularly automobile accidents. This can lead to serious physical disabilities. Use of certain drugs can lead to mental disabilities. These physical and mental disabilities can be developmental disabilities.

- Early regular use of alcohol and drugs seems to speed up the addiction process so that the process takes six months to a year rather than the many years that is typical for a person who began regular use as an adult (Kinney, 1987), (Mannelo, 1991), and (Monaco, 1991).

2. Prevention Strategies

- Begin education programs for children in kindergarten to build their self-esteem, resistance skills, and knowledge of the effect of alcohol and drugs. The programs should be continued throughout the school years K-12 and be supplemented with community programs.

- Activities that don't involve the use of alcohol and drugs should be developed/encouraged (Kinney, 1987), (Mannelo, 1991), and (Monaco, 1991).

II. References and Resources

A. References Used

Kinney, Jean and Leaton, Gwen. (1987). Loosening the Grip - A Handbook of Alcohol Information. St. Louis: Times Mirror/Mosby College Publishing.

Mannelo, Timothy A. (1991). Primary Prevention Education: A Primer. In Marcia Lawton (ed.), Prevention. Richmond: Virginia Commonwealth University.

Monaco, Philip C. (1991). Adolescent Addiction. In Elizabeth B. Whitley (ed.), Monograph on A Substance Abuse Colloquium. Richmond: Virginia Institute for Developmental Disabilities.

B. Resources

Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services

Virginia Department of Health

Virginia Department of Education

Virginia State Police

Alcoholics/Narcotics Anonymous

Al-Anon

C. Other References and Resources (complete with your own)

Environmental Exposures

I. Problem

There are environmental substances which can cause developmental disabilities if an infant or child is exposed to them. The most common one and the one presented here is lead poisoning.

- Lead is a lethal poison which can cause death, mental retardation, and other serious disabilities.

  - Lead can enter the body:
    - through the skin from powders and creams containing lead, often common in "old-fashioned" home remedies,
    - through the respiratory tract from the environmental fumes of leaded gasoline, and
    - through the gastrointestinal track from ingestion of lead-based paint chips and dust.

  - Sources of Lead:

    - The most prevalent source of lead poisoning in young children is lead-based paint. These paint chips have a sweet taste and are therefore appealing to children. Most cases of lead poisoning occur between the ages of one and six in run-down urban neighborhoods where old buildings with peeling paint and broken plaster are more likely to be found. This is a problem for all children but particularly those who exhibit pica behavior.

    - Other reported sources of lead poisoning include children ingesting lead from:
      - colored ink from newspapers and magazines,
      - imported toys with lead-containing paint,
      - inadequately glazed pottery,
      - water that is from old lead pipes, lead soldered pipes, and lead-lined water coolers, and
      - soil.

    - Sources also include:
      - factory sites,
      - burning old lead battery casings,
      - lead brought home on clothing by workers in lead smelters, battery plants, radiator repair

shops, etc.,
- dust and dirt in children's play areas contaminated by automobile exhaust, debris, and deterioration of lead containing paint from old houses, and
- fumes, dust, and debris created by removing lead-containing paints from old houses.

- Increased Body Burden of Lead:

  - Various studies of children who had been tested after having been diagnosed with exposure to lead showed the following long-term effects:
    - a range of neurologic dysfunctions,
    - various motor impairments,
    - poor fine motor coordination,
    - maladaptive behavior,
    - attention deficit disorders,
    - deficits in global IQ, and
    - hyperactive behavior.

  - These effects vary in number and severity of each child depending upon the length and degree of lead exposure.

  - Lead encephalopathy can also occur. The early symptoms of lead poisoning are often non-specific and difficult for the physician to interpret. Children can be anorexic, irritable, drowsy, apathetic, show a decreased interest in play activities, and/or can complain of abdominal pain. If these symptoms are longstanding they can lead to developmental delay or regression in development. The symptoms of the advanced stages of lead poisoning include vomiting, lethargy, excessive sleep, seizures, and coma.

  - Lead encephalopathy can cause death. Survivors can have seizure disorders, mental retardation, cerebral palsy, optic atrophy, and behavioral disturbances.

- Laboratory Tests:

  - Although early detection of lead poisoning is difficult, early suspicion leads to the specific screening methods of:
    - blood specimen (the most common),
    - urine specimen, and

- x-ray of the abdomen for presence of paint chips (Poe, 1982), (Senft & Pueschel, 1990), and (Needleman, 1991).

II. Prevention Strategies

- Lead poisoning is associated with social, educational, economic, medical, technical, and political factors.

- It is recommended that the control of childhood lead poisoning include the following:
  - members of the professional community and the general public should be educated about the dangers of lead poisoning and its prevention;
  - the children, particularly those at risk must be located, screened for lead poisoning, and treated if necessary; and
  - the environment in which children ingest lead-based paint must be located and eliminated. If other sources of lead poisoning are identified, they should also be eliminated.

- The Centers for Disease Control have established a minimum screening schedule for children aged six to 36 months and 36 to 72 months. A questionnaire should be administered at well child care visits to assess the potential for high-dose lead exposure and the appropriate frequency of screening.

  - The frequency of screening is based on age (6 to 36 months or 36 to 72 months) and risk (low risk and high risk).

  - Screening is done with a blood lead test. If tests results indicate a blood lead level of 15 or greater, follow-up including education, nutritional counseling, environmental history taking, environmental investigation, abatement, medical evaluation, and medical treatment is recommended (Needleman, 1991) and (Centers for Disease Control, 1991).

III. References and Resources

A. References Used

Centers for Disease Control. (1991). Preventing Lead Poisoning in Young Children. Atlanta: Author.

Needleman, Herbert L. (1991). Lead Exposure: The Commonest Environmental Disease of Childhood. Zero to Three. Vol XI, No. 5 June 1991, 1-5.

Poe, Elisabeth S. (1982). Prevention of Mental Retardation - A Manual for Community Program Development. Charlottesville: Region Ten Community Services Board.

Senft, Karen E. and Pueschel, Siegfried M. (1990). Lead Poisoning in Childhood. In Siegfried M. Pueschel and James A. Mulick (eds.), Prevention of Developmental Disabilities. Baltimore: Paul H. Brookes Publishing Company.

B. Resources

Virginia Department of Health

Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services

Alliance to End Childhood Lead Poisoning 202-543-1147

C. Other References and Resources (complete with your own)

Unintentional Injuries

I. Problem and Prevention Strategies

Trauma resulting from unintentional injuries is the primary cause of death in children over one year of age, as well as the cause of many illnesses or abnormal conditions that include both physical and emotional suffering (Dannenberg, 1991). A few of these are discussed below.

A. Moving Vehicle Accidents

1. Description

- Motor vehicle accidents, particularly automobile, cause many deaths and are one of the leading causes of injuries, disabilities, and death of children.
- Head injuries and spinal cord injuries result from automobile, ATV, motorcycle, and bicycle accidents.
- Infants and small children are at high risk in motor vehicle accidents because they are often not restrained in car safety seats or they are not properly restrained in car safety seats.
- Teenagers are at high risk for motor vehicle accidents. Teenage drivers are inexperienced and prone to risk taking. Teenagers often group together and socialize in automobiles sometimes while using alcohol and drugs.
- Driving while under the influence of alcohol and drugs puts not only the driver but all others on the highway at risk of being in an accident (Buckner, 1991), (O'Shea, 1990), and (Action for Prevention, 1989).

2. Prevention Strategies

- All automobiles are required by law to have restraining devices. At a minimum, automobiles have seat belts. Some automobiles now come equipped with more advanced restraining devices such as air bags.
- Restraining devices are of no help in preventing injuries unless they are used. Virginia law requires front seat driver and passengers to wear seat belts.

- Infants and young children should not only be restrained in seat belts, they should be in appropriate and approved car safety seats. It is important that parents know how to properly install the infant seats and how to use them. Virginia law requires children four and under and/or children under 40 pounds to be restrained in a car safety seat.

- Emphasis should be placed on teenagers being properly trained to drive and encouraged to practice responsible alcohol and drug free driving. Virginia law requires teenagers to complete Driver's Education before they can apply for a driver's license.

- There should be continuing public education efforts on wearing seat belts and using infant seats.

- There should be education programs about the hazards of using alcohol and drugs while driving and stiff penalties for anyone convicted of driving under the influence of alcohol and/or drugs (Buckner, 1991), (O'Shea, 1990), and (Action for Prevention, 1988).

B. Cycle Accidents

1. Description

- Bicycle Accidents: A number of children die each year while riding bicycles, nearly all of these are due to collision with another vehicle. Many more children are injured while riding bicycles. In most cases, children under age 12 are responsible for causing the accident by unsafe cycling or failing to obey traffic signs and signals. Head and neck injuries are common.

- Motorcycle Accidents: A number of children (mostly adolescent) die each year due to motorcycle accidents. Many others are injured. Head injury is the most common one. After head injury, the next most common injury is to the legs. Leg injury due to motorcycle accidents is the most common cause of hospitalization for leg trauma.

- All Terrain Vehicles (ATV): All terrain vehicles also cause death and injury. Many parents do not realize how dangerous

these are. They are hard for children to handle. They are often used on paved roads and they were not meant to be due to their soft tires (Buckner, 1991) and (O'Shea, 1990).

2. Prevention Strategies

- Children should have bicycles that are in good condition and are a good fit/size for them.
- Children and parents should be exposed to a bicycle safety program.
- All children should wear Snell approved helmets when riding a bicycle.
- Children should be provided safe places to ride bicycles.
- Motorcycle safety programs should be available.
- Helmets should be worn when riding a motorcycle. Virginia law requires motorcyclists to wear helmets.
- Educational information should be made available to parents on the dangers of children riding ATVs (Buckner, 1991) and (O'Shea, 1990).

C. Pedestrian Injuries

1. Description

- Many children and adolescents die each year as a result of pedestrian injuries. Many others sustain serious injuries. Head and spinal cord injury can occur (Buckner, 1991) and (O'Shea, 1990).

2. Prevention Strategies

- Education for children and their parents is the best prevention strategy (O'Shea, 1990).

D. Water Mishaps

1. Description

- A few drownings or near drownings in older children are caused by voluntary hyperventilation which allows swimmers to hold their breath much longer while swimming.

- Head and neck injuries result from diving in shallow water.

- However, most drownings do not occur while swimming/diving. They occur among poorly supervised children who cannot swim. Specifically, 95 percent of all reported drownings or near drownings occur in swimming pools, swimming holes, bathtubs, or at beaches with children not being adequately supervised. Children who are submerged in water for an extended period of time can suffer brain damage (Lawrence, 1991) and (O'Shea, 1990).

2. Prevention Strategies

- Close parental/adult supervision is necessary for all infants and young children when bathing, swimming, boating, or in any way around large containers or bodies of waters.

- Children should be taught how to swim as well as rules of water safety. They still need supervision when swimming or boating. They should be taught never to dive in unknown waters.

- Swimming pools should be enclosed in fencing.

- Life guards should be on duty at public swimming pools (Lawrence, 1991) and (O'Shea, 1990).

E. Thermal Injuries

1. Description

- Scalds are the most common cause of thermal injuries. About 75 percent of all scalds occur in kitchens, usually from water heated on stoves. Most other scalds occur in bath tubs.

- Burns from fire are another common cause of thermal injuries (O'Shea, 1990).

2. Prevention Strategies

- Lower thermostats on hot water heaters to 130 degrees or lower.
- Supervise children in baths, around stoves, heaters, and fireplaces, etc.
- Use flame resistance sleep wear for children.
- Encourage families to have a home safety plan.
- Use fire and smoke detectors in homes as required by Virginia law. Routinely check the smoke detectors.
- Encourage schools to participate with fire departments and other agencies in fire safety education programs.
- Make educational programs for children and their parents available in fire safety (O'Shea, 1990).

F. Poisoning

1. Description

- Another childhood unintentional injury which can cause death and injuries is poisoning. Poisoning can cause brain damage and mental retardation. Poisoning can happen from medicines, household cleaning products and other products used around the house, plants, etc. (Poe, 1982) and (O'Shea, 1990).

2. Prevention Strategies

- Educate parents about the dangers of poisoning, child proofing techniques againt poisoning, and having Syrup of Ipecac on hand to give the child in case of certain types of poisoning.

- Parental/adult supervision of infants and young children is the best prevention strategy for poisoning.

- Other strategies include:

  - Child resistant packaging for medicine.

  - Safety tops on cleaning and other household products.

  - Locks on cabinets where medicine and household products are kept.

  - Educating young children about the dangers of household products, plants, etc. (O'Shea, 1990).

G. Falls

1. Description

   - A large number of falls occur for children on the playground. Swings account for 43 percent of playground injuries, various types of climbing apparatus account for about 27 percent, and sliding boards account for about 15 percent. Falls from trampolines account for other injuries. These falls can be severe, some resulting in quadriplegia (Sanders, 1991), (Poe, 1982) and (O'Shea, 1990).

2. Prevention Strategies

   - Again, supervision by parents/adults of young children is important in prevention of falls.

   - Playground equipment should be properly installed and maintained.

   - Playgrounds, particularly areas under equipment, should have surfaces to cushion falls (sand, rubber, mulch. etc).

   - Children should be taught the proper way to play on various playground equipment.

   - Child care centers, schools, parks, and other places where children play should provide safe environments for play

(Sanders, 1991) and (O'Shea, 1990).

H. Suffocation

1. Description

- Suffocation is another leading cause of accidental death in infancy and young children.

- Suffocation can be mechanical or can result from ingestion of food or small objects. Mechanical suffocation deaths in young children are usually due to entrapment in cribs and playpens. Safety pins are among the small objects frequently ingested by infants. In toddlers, choking and suffocation are usually related to inappropriate eating habits. Suffocation can also come from a child becoming trapped in heavy bedding or plastic.

- Even if suffocation does not lead to death, prolonged time without oxygen can lead to brain damage (Action for Prevention, 1989).

2. Prevention Strategies

- Educate parents about suffocation, child proofing techniques, and how to use the Heinlich technique for some types of suffocation.

- Cribs and play pens should conform to standards which have been established to prevent entrapment.

- Small objects that can be swallowed should be kept out of the reach of infants and small children.

- Young children should be educated not to put small objects in their mouths.

- Young children should be taught the proper way to eat and then be supervised while eating.

- Heavy bedding and particularly plastic bags should be kept away from infants and young children.

- Supervision by parents/adults of infants and small children is important (Action for Prevention, 1989).

II. References and Resources

A. References Used

Action for Prevention, Inc. (1989). The Virginia Agenda for Prevention of Developmental Disabilities: A Resource Document. Richmond: Virginia Institute for Developmental Disabilities.

Buckner, Janet. (1991). Motor Vehicle/Bike/ATV/Pedestrian Safety. In Elizabeth B. Whitley (ed.), Monograph on Child Injury Prevention. Richmond: Virginia Institute for Developmental Disabilities.

Dannenberg, Andrew L. (1991). The Prevention of Childhood Injuries: A National Overview. In Elizabeth B. Whitley (ed.), Monograph on Child Injury Prevention. Richmond: Virginia Institute for Developmental Disabilities.

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Poe, Elisabeth S. (1982). Prevention of Mental Retardation - A Manual for Community Program Development. Charlottesville: Region Ten Community Services Board.

Sanders, Jeanne K. (1991). Playground Safety. In Elizabeth B. Whitley (ed.), Monograph on Child Injury Prevention. Richmond: Virginia Institute for Developmental Disabilities.

B. Resources

Virginia Department of Health

Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services

Please Be Seated Program under the Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services

Virginia Department of Motor Vehicles

American Red Cross

Safe Kids Coalition 1-800-523-6019

University of Virginia

Medical College of Virginia, Virginia Commonwealth University

C. Other References and Resources (complete with your own)

Child Abuse and Neglect

I. Problem

- Child abuse and neglect is defined in terms of the following categories:
  - Physical harm or neglect (this includes inadequate/inappropriate supervision);
  - Mental or emotional harm or neglect; and
  - Sexual abuse or molestation.

- Abuse and neglect usually begin at an age when the child is unable to meet his or her own needs. This may coincide with the final stages of brain development. Severe physical abuse during a time when the bones of the skull are still soft can cause permanent brain damage, mental retardation, broken bones, and/or injury to major organs.

- The practice by some parents of shaking their infants has occurred with enough frequency that the results have been named, shaken infant syndrome. Shaking an infant (for any reason) may cause skeletal and/or cerebral vascular lesions and reportedly, is a frequent cause of later mental retardation and permanent brain damage.

- Severe abuse and/or neglect (particularly physical) can cause death or developmental disabilities. Other less severe abuse and/or neglect of all types can damage a child's development. The attachment or bonding between mother and child at birth and during early infancy is critical to the child's future development. Other positive parental/adult relationships are also critical to the child's future development. If this attachment/bonding/positive relationship is missing, the child can have developmental delays including problems with cognition, verbal skills, and language. The child can also have mental health problems.

- Often, child abuse and neglect occur simultaneously. They can be intentional or unintentional.

- There is a relationship between domestic violence and child abuse and neglect.

- There is a relationship between alcohol and drug use/abuse and child abuse and neglect.

- Children who have been abused and neglected are likely to abuse and neglect their children when they become parents (Poe, 1982), (Fotheringham, et al., 1983), (Pawelski, 1991), and (Childress, 1991).

II. Prevention Strategies

- Prevention begins with information and education.

- Some specific information and education strategies are:

  - Teach living and parenting skills to adolescents before they become parents.

  - Teach the importance of choosing to become a parent rather than becoming one by accident.

  - Create appropriate expectations regarding child rearing for expectant parents through prenatal classes.

  - Teach children (as early as nursery school and ongoing through grades K-12) to protect themselves from all forms of abuse and neglect.

  - Increase community awareness of the potential for child abuse in families.

  - Increase professional awareness of the potential for and identification of child abuse and neglect and to report it as appropriate.

  - Encourage parents to seek counseling when family tensions threaten to result in child abuse.

  - A key prevention strategy is the reporting of abuse and neglect or suspected abuse to local child protection agencies. The benefits to the abused child will be gained almost immediately. Supervision may be offered, or the child may be removed from the home until it is safe to return. Families should receive the appropriate support to prevent the problem(s) from recurring. In some cases, permanent removal to foster or adoptive homes may be necessary.

  - Intervention should occur when there is potential (as well as actual) child abuse and neglect. The following are two different methods of intervention with varying degrees of effectiveness:

    1. Traditional psychotherapy is often successful for middle and upper income families. However, it appears to be less effective for lower income families and cost is an important factor.

2. Self-help groups such as Parents Anonymous in which parents support one another and exchange ideas on parenting is practical and a less expensive approach than psychotherapy. (Poe, 1982), (Fotheringham, et al., 1983), (Pawelski, 1991), and (Childress, 1991).

3. Another intervention which should occur is parenting programs which teach nurturing, child growth and development, appropriate expectations, behavior management, etc.

III. References and Resources

A. References Used

Childress, Ann. (1991). A State Perspective on Child Abuse and Neglect. In Elizabeth B. Whitley (ed.), Monograph on Child Abuse and Neglect Colloquium. Richmond: Virginia Institute for Developmental Disabilities.

Fotheringham, John B.; Hambley, Walter D.; Haddad-Curran, Harriet W. (1983). Prevention of Intellectual Handicaps. Toronto: The Martin Group.

Pawelski, Christine E. (1991). A National Perspective on Child Abuse and Neglect and Developmental Disabilities. In Elizabeth B. Whitley (ed.), Monograph on Child Abuse and Neglect Colloquium. Richmond: Virginia Institute for Developmental Disabilities.

Poe, Elisabeth S. (1982). Prevention of Mental Retardation - A Manual for Community Program Development. Charlottesville: Region Ten Community Services Board.

B. Resources

Virginia Department of Social Services

Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services

Virginia Department of Health

Virginia Department of Education

Virginians for Child Abuse Prevention, Inc.

National Coalition on Child Abuse and Disabilities 212-620-2043

Child Abuse and Neglect Hotline 1-800-552-7096

C. Other References and Resources (complete with your own)

PRIMARY PREVENTION OF DEVELOPMENTAL DISABILITIES

DEVELOPMENT OF PROGRAMS AND PROJECTS

Overview

The previous sections have discussed some of the causes of developmental disabilities and prevention strategies. As can be seen when reviewing the previous sections, the problems and the prevention strategies are numerous and often complex.

The Committee on a National Agenda for the Prevention of Disability sets out developmental disabilities and their prevention in the following way:

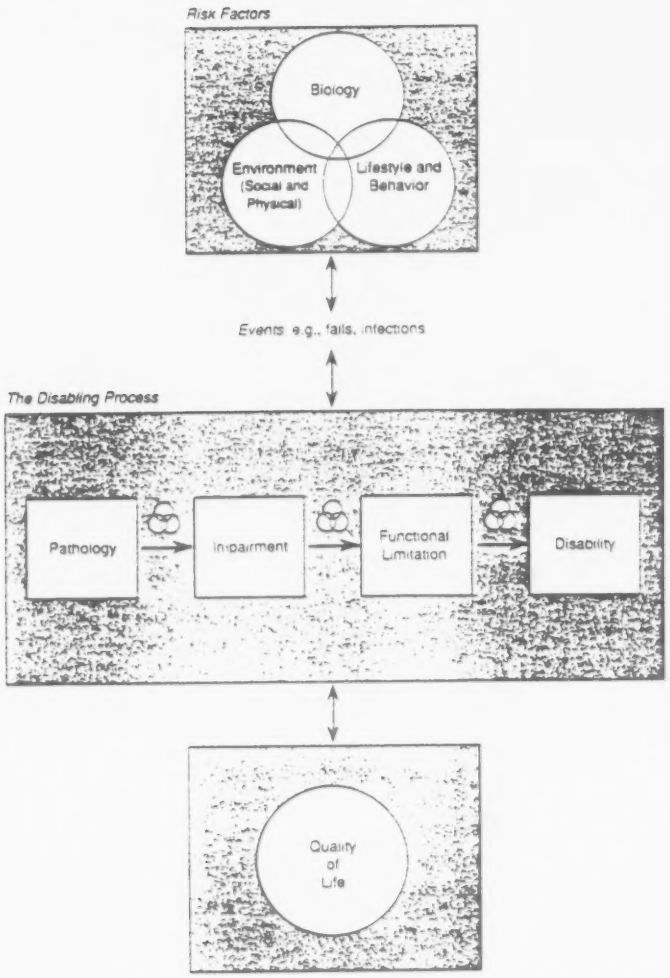
The disabling process has four distinct stages: 1. Pathology which is the interruption or interference of normal bodily processes or structures; 2. Impairment which is loss and/or abnormality of mental, emotional, physiological, or anatomical structure or function; 3. Functional limitation which is restriction or lack of ability to perform an action or activity in the manner or within the range considered normal that results in impairment; and 4. Disability which is the inability or limitation in performing socially defined activities and roles expected of individuals within a social and physical environment. One stage can progress to another, but depending on circumstances the progression can be halted or reversed. Therefore, prevention efforts can be directed at all of the stages including the actual disability stage.

In addition, risk factors influence each stage of the disabling process. Risk factors are biological, environmental (social and physical), and lifestyle or behavioral characteristics. Identification of these risk factors can help in developing prevention efforts.

Finally, quality of life affects and is affected by the outcomes of the stages of the disabling process. This is an important concept when considering how individuals will respond to prevention efforts.

These concepts - disabling process, risks factors, and quality of life - and the concept of prevention come together in the model presented in the diagram on the following page (Committee on a National Agenda for the Prevention of Disability, Institute of Medicine, 1991).

The above discussion points out how important it is to clearly define the major problems causing developmental disabilities (these can vary from locality to locality) and develop prevention efforts to address the major problems. It also points out the complexity of developmental disabilities and their prevention and the need to involve many agencies/organizations/disciplines in the prevention efforts. This best serves individuals and utilizes scarce resources of agencies and organizations. It is also possible to look for grants and other special funding for prevention programs and projects. Many funding



Model of disability showing the interaction of the disabling process, quality of life, and risk factors. Three types of risk factors are included: biological (e.g., Rh type); environmental (e.g., lead paint [physical environment], access to care [social environment]); and lifestyle and behavior (e.g., tobacco consumption). Bidirectional arrows indicate the potential for "feedback." The potential for additional risk factors to affect the progression toward disability is shown between the stages of the model. These additional risk factors might include, depending on the stage of the model, diagnosis, treatment, therapy, adequacy of rehabilitation, age of onset, financial resources, expectations, and environmental barriers.

sources are particularly interested in interagency/organization proposals and most require letters of support from appropriate agencies and organizations.

I. Needs Assessment

- Before deciding on a primary prevention program or project to implement, a needs assessment should be conducted. This can be formal/informal, large scale/small scale, complex/simple, but it should be done.

- This first step in conducting a needs assessment is to identify problems causing developmental disabilities in the locality. There is a lot of existing data that can be used in the needs assessment. This section has data on a number of data elements at the State level. Most of these data elements are collected, maintained, and retrieved by agency computerized information systems. Most of these data elements are available by locality. These data elements are just some of the ones that are already being collected that can be used. Many of the State agencies and their local counterparts (for example, the Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services and the local community services boards and the Virginia Department of Social Services and the local departments of social services) are required to develop State plans, and these are in some way based on need. These plans are available to be used. These data can be used exclusively in identifying needs, or they can be used to identify key areas for further data collection.

- In addition to collecting existing data, new data can be collected on needs. The first place to collect data is in the agency and then in other appropriate agencies and organizations. Data can be collected from agency/organization directors as well as staff. This can be done in meetings where people list and prioritize the needs, or it can be done by surveys - either in-person, phone, or mail. Data can also be collected from clients, their families, and/or the general public. Again, this can be done in meetings where people identify and prioritize the needs and by in-person, phone, or mail surveys.

- The second step in conducting a needs assessment (once the problems are determined and prioritized) is to identify any existing programs/projects/resources that address the problems.

- The third step in conducting a needs assessment (once the problems are determined and prioritized) is to identify gaps in programs/projects/resources and barriers in addressing the problems.

- These two steps can be done in the agency, other appropriate agencies and organizations, and even local businesses. Again, the data collection can be done in meetings and by in-person, phone, or mail surveys from agency/organization directors, staff, and other key people.

- Data collection can be a few key questions where the answers are manually tallied, or it can be many questions where the answers are computerized. The data collection can occur all at once or in several stages. The data collection can occur over a number of weeks or months.

- Data analysis occurs after data collection and can be simple or complex. It can and probably will involve basic descriptive statistics such as frequencies, percentages, averages, ranges, etc.

- Data collection and the analysis of it is a tedious and time consuming process. It can also be an expensive process. It should be kept in mind, however, that this process is important and the basis for implementing programs and projects.

- The person or persons responsible for conducting a needs assessment should have a number of people available in the agency to consult with them and ideally a group of interagency/organization people available to consult with them on the data collection and analysis. College and university students are often looking for class projects. If there is a college or university in the locality, a student might be available to conduct the needs assessment.

- Once the needs assessment is completed, it should be written up in a formal report. Again, this report can be simple or elaborate but it should be geared to the audience (agency directors, agency boards, boards of supervisors, general public, etc).

II. Planning

- Once problems have been identified and prioritized, any existing programs/projects/resources available to address the problems have been identified, and gaps in programs/projects/resources and barriers in addressing the problems have been identified, it is appropriate to determine what area of primary prevention of developmental disabilities and what type of programs or projects should be chosen to be implemented.

- It is extremely important at this point to review the literature and, possibly formally or informally, survey others in the locality, other localities, the state,

Prevention of Developmental Disabilities

_____ Program/Project SAMPLE

Goal # _____

_____

Objective # _____

_____

Tasks/Activities	Time Line Program/Project Month												Person(s) Responsible
	1	2	3	4	5	6	7	8	9	10	11	12	

etc. to identify if programs or projects already exist in other places that would address the problem in whole or in part. The next section presents a few primary prevention programs/projects in the State. Any time a program/project can be based on another program that has already proven to be successful, it should be. In replicating another program or project in whole or in part, it is important to consider and make adjustments for differences in populations, locations, etc.

- If there has not been interagency/organization involvement in the needs assessment and decision making up to this point, it should occur now. It is important to get input and commitment from all appropriate people/agencies/organizations in the planning of a program or project on the prevention of developmental disabilities.

- Once the program or project has been identified based on the problems, the goals of the program or project should be identified. The goals identify the way to address the problem. The goals are general statements on what the program or project plans to accomplish. Goals should be achievable and kept to a reasonable number (possibly five or less).

- Every goal identified should have objectives to further define it. Objectives are measurable, specific, statements. Objectives have four parts:

1. What? (the activity)
2. Who? (target group)
3. How many? (the number of people/sessions/etc.)
4. When? (the completion)

Objectives should be realistic. As the program or project is implemented, monitored, and evaluated, the objectives can be modified.

- Finally, every objective should have tasks. These are specific activities that lead to completing the objective. All key activities should be identified in the order they should occur.

- The plan for the program or project including all goals, objectives, and tasks should be reviewed, approved of, and committed to by all participating agencies and organizations. It is at this time that special roles and responsibilities are identified and resources are committed.

- Once goals, objectives, and tasks have been identified and defined, the evaluation plan of the program or project should be designed. It is critical that the evaluation plan is designed before the program or project is implemented.

III. Evaluation

- Evaluation is critical in any program or project for the prevention of developmental disabilities. Evaluation assists in monitoring the program or project on an ongoing basis. This ensures the program or project is being implemented as planned and that changes in the implementation are made in a timely way if necessary. Evaluation assists in describing the project. This is critical as part of the overall evaluation as well as documenting the program or project for replication purposes. Evaluation also assists in determining the effectiveness (outcomes/impacts) of the program or project and provides a basis for continuing the program or project and replicating it.

- In order to monitor the program or project, describe it, and begin to determine the effectiveness, process evaluation is used. Process evaluation answers the questions like what? who? how? when? Process evaluation provides detailed information on the tasks/activities of the program or project. In order to determine the effectiveness of the program or project, outcome evaluation which looks at short-term effects or impact evaluation which looks at long-term effects is used. Effects can be individual or system. Outcome and impact evaluation provides information on the goals and objectives of the programs and projects. In this time of diminishing resources, evaluation becomes the basis for proving program/project accountability and determining future funding.

- Process evaluation involves detailed record keeping of the program or project. This record keeping should be done by project staff and/or evaluator in a formal way. This record keeping documents what was done (activity), who was involved (staff and participants) and how many, how it was done, and when it was done. Costs of the program or project are important to capture. Process evaluation can also involve data collection from staff and/or participants to collect details. For example, it can be important to capture the race, sex, age, education level, etc. of the staff and/or the participants. Data collection instruments can be developed for this.

- Outcome and impact evaluation involves data collection. This data collection can be from existing data collection systems (like many of the data elements later in this section) and/or it can be from data collection instruments (either instruments in existence but used also for this program or project or instruments designed especially for this program or project). The data collection can also come from meetings, interviews, etc. where information is gathered and summarized.

Prevention of Developmental Disabilities

_____ Program/Project SAMPLE

Evaluation Design

Goal # _____

_____

Objective # _____

_____

Evaluation Questions	Method of Collection	Source of Collection	Time of Collection

- Data collection occurs at different times of the program or project. Some data collection can occur at the beginning (pre) of the program or project and some can occur at the end (post). Some data are collected at the beginning (pre) and the same data can be collected at the end (post) of the program or project and the changes in the data can be determined. Some data can be collected routinely during the program or project.

- Once it is decided what data are being collected, when, and how, it can then be decided how to analyze the data. Data can be manually compiled and tallied or computerized. The analysis can be simple such as counting the numbers (frequencies) and computing the percentage or it can be complex such as measuring change scores.

- As with the needs assessment, evaluation data can be formal/informal, large scale/small scale, complex/simple. In any case, it is a tedious and time consuming process and can be an expensive process. Evaluation is, however, critical to the program or project.

- The person or persons responsible for conducting an evaluation should have people available in the agency to consult with them and ideally a group of interagency/organization people to consult with them on the data collection and analysis. The person(s) responsible for conducting an evaluation can be involved with the program or project, external to the program or project (either from the agency or a consultant), or possibly a student from a local college or university.

- Once the data are collected and analyzed, they should be used ongoing (formative evaluation) and formally written-up and disseminated at the end of the program or project (summative evaluation). Interim formal evaluation reports are important if the program or project is several years in duration. These evaluations can be used to make needed modifications to the program/project.

- It should be kept in mind that there are differences in evaluating prevention programs/projects (particularly primary prevention) from other programs/projects. These differences are as follows:

  1. Prevention efforts focus on populations at risk rather than individuals who have exhibited problems.

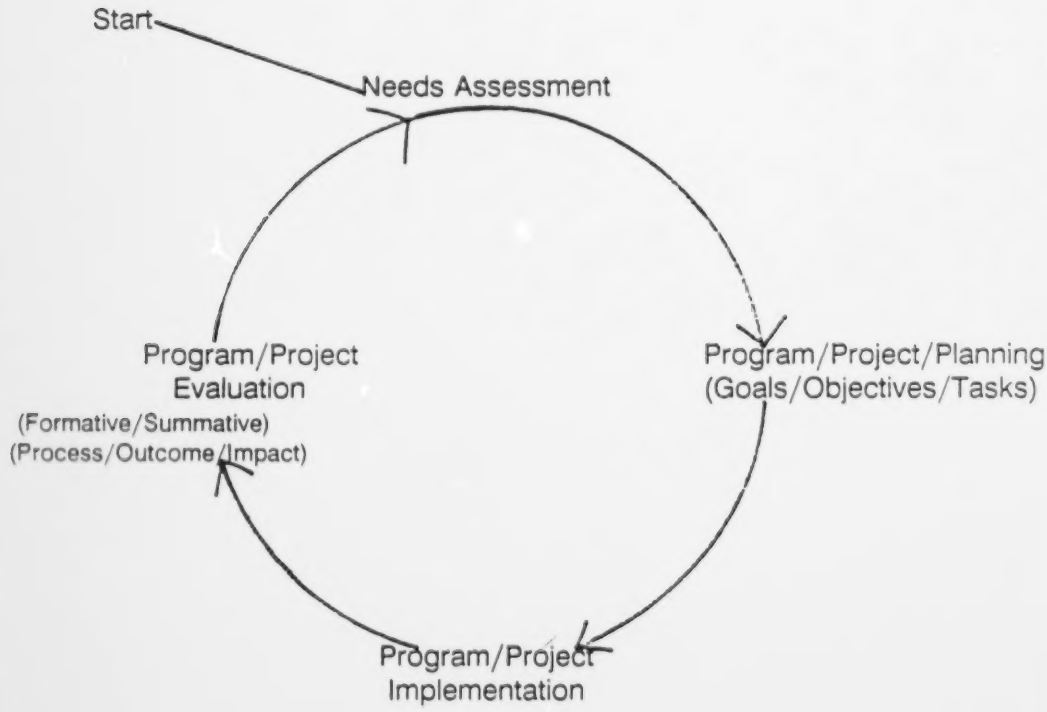
  2. Prevention efforts often intervene at a system level rather than an individual level.

3. Prevention efforts have as goals the non-occurrence of certain problems.

4. Prevention efforts often have long-term goals, possibly five, ten or more years in the future (Galano and Nezlek, 1986).

IV. Summary

. A diagram can summarize the previous discussion on developing prevention programs or projects.



. This process of developing prevention efforts is ongoing and should involve all appropriate agencies/organizations/disciplines in all phases.

V. 43 Data Elements

. In 1986, Dr. Allen C. Crocker of the Developmental Evaluation Clinic,

Children's Hospital, Boston, Massachusetts developed a design for the study of effects of mental retardation/developmental disabilities prevention efforts. The design has 43 data elements to collect and record. The design is called the "fateful forty-three" because of the data elements' relationship with the stakes for present and future children (Crocker, 1986).

Since numerous efforts for the prevention of developmental disabilities have been undertaken over the years in Virginia, these 43 data elements have been collected for Virginia. These data elements are presented in this document for 1985-1990. Each data element is discussed, the data are present (for six years whenever possible), and the source of the data is given. Not only can the data be used to evaluate previous and current prevention efforts, they can also be used in needs assessments.

VI. References Used

Committee on a National Agenda for the Prevention of Disabilities, Institute of Medicine. (1991). Disability in America. Washington, D.C.: National Academy Press.

Crocker, Allen C. (1986). Data Collection for the Evaluation of Mental Retardation Prevention Activities: The Fateful Forty-Three. An unpublished document completed as a result of grant activity at the Development Evaluation Clinic at the Children's Hospital in Boston, Massachusetts.

Galano, Joseph and Nezlek, John B. (1986). Evaluating Prevention Programs: A Training Manual. Richmond: Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services.

Virginia Projected Population

Population is projected annually in Virginia based on census data and other surveys.

	Projected Population					
	July 1985	July 1986	July 1987	July 1988	July 1989	Census July 1990
Age						
0-4	387,020	392,200	397,370	402,530	407,710	363,636
5-9	397,580	399,490	401,400	403,300	405,210	424,361
10-14	412,380	408,530	404,690	400,850	397,000	398,531
15-19	475,910	469,850	463,770	457,710	451,630	438,556
over 19	4,053,070	4,130,080	4,207,080	4,284,010	4,360,980	4,512,274
Total	5,725,960	5,800,150	5,874,310	5,948,400	6,022,530	6,137,358
	29% 19 and under	29% 19 and under	28% 19 and under	28% 19 and under	28% 19 and under	26% 19 and under

Source: Virginia Employment Commission, Virginia State Data Center, 703 East Main Street, 23219, 804-786-8308

1. **Utilization of Family Planning Facilities**

Family planning services encourage people to plan pregnancies to ensure children are wanted and that people are prepared to have and raise them. Family planning services usually reach only a small number of people judged to be in need of them. In Virginia, family planning services are offered by a number of public and private agencies and organizations. The one public agency that has responsibility for family planning services is the Virginia Department of Health. Services are delivered by the local health departments.

Number of People Receiving Family Planning Services

FY 1985	FY 1986	FY 1987	FY 1988	FY 1989	FY 1990
89,187	88,888	89,008	88,530	82,704	80,648
29 % of these were 19 and younger	33% of these were 19 and younger	33% of these were 19 and younger	29% of these were 19 and younger	28% of these were 19 and younger	28% of these were 19 and younger

Source: Virginia Department of Health, Division of Family Planning, 109 Governor Street, Richmond, Virginia, 23219, 804-786-5916

2. **Statistics on Genetic Counseling Services**

Genetic counseling services (here defined as prenatal diagnosis) are offered by a number of public and private agencies and clinics. These services are offered to prospective parents when there is concern about a hereditary illness, chromosomal disorders, congenital anomalies, and fetal loss. The genetics program for the state, administered by the Virginia Department of Health, supports programs at the Medical College of Hampton Roads in Norfolk, the Medical College of Virginia/VCU in Richmond, the University of Virginia in Charlottesville, the Genetics and IVF Institute in Fairfax, and the Virginia Sickle Cell Anemia Awareness Program in Richmond.

Number of Prenatal Diagnostic Patients*

FY 1985	FY 1986	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
1,206	3,430	3,818	1,952	1,964	3,822	6,310
68 tests with abnormal results	175 tests with abnormal results	212 tests with abnormal results	252 tests with abnormal results	167 tests with abnormal results	162 tests with abnormal results	294 tests with abnormal results

* The number variations are due to reporting difficulties.

Source: Medical College of Virginia for Mid Atlantic Regional Human Genetics Network, Box 33 MCV Station, Virginia Commonwealth University, Richmond, Virginia, 23298, 804-786-9632

3. **Genetic Carrier Testing**

Genetic carrier testing is offered by a number of public and private agencies and clinics. This testing determines if prospective parents carry diseases such as Tay-Sachs, Sickle Cell Anemia, etc. The genetics program for the state, administered by the Virginia Department of Health, supports programs at the Medical College of Hampton Roads in Norfolk, the Medical College of Virginia/VCU in Richmond, the University of Virginia in Charlottesville, the Genetics IVF Institute in Fairfax, and the Virginia Sickle Cell Anemia Awareness Program in Richmond.

Number of Genetics Clinic Patients*
(Patients with Existing Problems)

FY 1985	FY 1986	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
820	944	1,144	856	1,010	1,764	1,649

Number of Hemoglobinopathy Patients

CY 1985	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
13,185	14,006	17,055	14,264	* 12,181	12,334
1,988 tests with abnormal results	1,703 tests with abnormal results	2,108 tests with abnormal results	1,638 tests with abnormal results	1,457 tests with abnormal results	1,398 tests with abnormal results

*The number variations are due to reporting difficulties.

Source: Medical College of Virginia for Mid Atlantic Regional Human Genetics Network, Box 33 MCV Station, Virginia Commonwealth University, 23298, 804-786-9632

4. **Availability of Prenatal Care in Public Programs**

Early and regular prenatal care is important in any pregnancy to assist in ensuring a positive pregnancy and producing a healthy infant. Prenatal care in public programs is the responsibility of the Virginia Department of Health. Care is provided through the local health departments.

Number of Women Receiving Prenatal Care

CY 1985	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
13,685	14,679	14,917	not available - the information system was discontinued - there is a new information system currently being developed		

Source: Virginia Department of Health, Division of Maternal and Child Health, 109 Governor Street, Richmond, Virginia, 23219, 804-786-7367

5. **Percentage of Women Receiving Adequate Prenatal Care**

Information on prenatal care is captured on birth certificates and the information then becomes part of Virginia's vital statistics. Adequate prenatal care is defined as nine prenatal visits commencing during the first trimester of pregnancy.

Number and Percent of Live Births by Number of Prenatal Visits

	CY 1985	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
None	778 (1%)	829 (1%)	874 (1%)	1,088 (1%)	1,509 (2%)	not
Less than 5	3,234 (4%)	3,420 (4%)	3,399 (4%)	3,598 (4%)	3,690 (4%)	available
5-9	17,900 (21%)	18,839 (22%)	19,395 (21%)	18,748 (20%)	19,199 (20%)	yet
10-14	52,320 (61%)	52,181 (60%)	53,717 (59%)	56,027 (60%)	58,239 (60%)	
Over 14	11,082 (13%)	11,471 (13%)	11,976 (13%)	12,382 (13%)	12,610 (13%)	
Unknown	670 (1%)	385 (1%)	953 (1%)	973 (1%)	1,291 (1%)	
Total	85,984	87,125	90,314	92,816	96,538	
	74% adequate	73% adequate	73% adequate	74% adequate	73% adequate	
	54% adequate for 19 and under	56% adequate for 19 and under	57% adequate for 19 and under	59% adequate for 19 and under	56% adequate for 19 and under	

Number and Percent of Live Births by Trimester Prenatal Care Began

	CY 1985	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
None	778 (1%)	829 (1%)	874 (1%)	1,088 (1%)	1,509 (2%)	not
1st	68,209 (79%)	69,527 (80%)	72,576 (80%)	74,091 (80%)	76,305 (79%)	available
2nd	13,873 (16%)	13,794 (16%)	13,605 (15%)	13,932 (15%)	15,056 (16%)	yet
3rd	2,619 (3%)	2,669 (3%)	2,636 (3%)	2,800 (3%)	2,986 (3%)	
Unknown	505 (1%)	306 (1%)	623 (1%)	905 (1%)	682 (1%)	
Total	85,984	87,125	90,314	92,816	96,538	
	79% adequate	80% adequate	80% adequate	80% adequate	79% adequate	
	57% adequate for 19 and under	58% adequate for 19 and under	60% adequate for 19 and under	58% adequate for 19 and under	56% adequate for 19 and under	

Source: Virginia Department of Health, Center for Health Statistics, 109 Governor Street, Richmond, Virginia, 23219, 804-786-6206

6. **Utilization of Maternal Serum Alpha-fetoprotein Assay**

Maternal serum alpha-fetoprotein assay is a test used to detect abnormal levels of alpha-fetoprotein in a pregnant woman. Elevated levels indicate a risk of fetal open neural tube defects and low levels indicate risk of infant Down Syndrome. Genetic testing is offered by a number of public and private agencies and clinics. The genetics program for the state, administered by the Virginia Department of Health, supports programs at the Medical College of Hampton Roads in Norfolk, the Medical College of Virginia/VCU in Richmond, the University of Virginia in Charlottesville, the Genetics and IVF Institute in Fairfax, and the Virginia Sickle Cell Anemia Awareness Program in Richmond.

There are no statewide data available from the Centers at this time.

Source: Virginia Department of Health, Division of Maternal and Child Health, 109 Governor Street, Richmond, Virginia 23219, 804-786-7367

7. **Utilization of Amniocentesis for Women 35 Years of Age and Older**

Amniocentesis is a test used to determine a woman's risk for chromosomal aberrations in their infants. This test is particularly useful for women 35 and older who are at high risk. Genetic testing is offered by a number of public and private agencies and clinics. The genetics program for the state, administered by the Virginia Department of Health, supports programs at the Medical College of Hampton Roads in Norfolk, the Medical College of Virginia/VCU in Richmond, the University of Virginia in Charlottesville, the Genetics and IVF Institute in Fairfax, and the Virginia Sickle Cell Anemia Awareness Program in Richmond. This information is for all amniocentesis regardless of age, but most patients having amniocentesis are 35 and older.

ChorionicVillus Sampling (CVS) is a new procedure to determine women's risk for chromosomal aberrations in their infants. It can be done earlier in the pregnancy than amniocentesis.

Number of Diagnostic Amniocentesis Procedures*

FY 1985	FY 1986	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
999	2,386	2,461	1,331	1,491	2,727	3,247
19 procedures with abnormal results	44 procedures with abnormal results	43 procedures with abnormal results	14 procedures with abnormal results	26 procedures with abnormal results	abnormal results not available	

* The number variations are due to reporting difficulties.

Number of Diagnostic CVS Procedures

1989	1990
1,901	2,732

Source: Medical College of Virginia for Mid Atlantic Regional Human Genetics Network, Box 33 MCV Station, Virginia Commonwealth University, Richmond, Virginia, 23298, 804-786-9632

8. **Teenage Births/Teenage Fertility Rates**

Information on age of mother at the time of birth is captured on birth certificates and the information then becomes part of Virginia's vital statistics. Rate information is based on teenage births per 1,000 females with under 15 based on the population age 14 and 15-19 based on the population age groups 15-44.

Number of Teenage Live Births and Fertility Rates

	CY 1985	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
Under 15	254 rate 6.3	286 rate 7.1	220 rate 5.5	235 rate 5.9	258 rate 6.6	not available yet
15-19	10,242 rate 44.1	10,189 rate 44.4	10,052 rate 44.4	10,179 rate 45.6	11,090 rate 50.3	
Total	10,496	10,475	10,272	10,414	11,348	
	12% of all live births	12% of all live births	11% of all live births	11% of all live births	12% of all live births	

Source: Virginia Department of Health, Center for Health Statistics, 109 Governor Street, Richmond, Virginia, 23219, 804-786-6206

9. **Out-of-Wedlock Birth Rates**

Information on marital status of mother at the time of birth is captured on birth certificates and the information then becomes part of Virginia's vital statistics. Rate information is based on out-of-wedlock births per 1,000 live births.

Number and Rate of Out-of-Wedlock Live Births

CY 1985	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
18,421 rate 214.2	19,493 rate 223.7	20,515 rate 227.2	22,072 rate 237.8	24,390	not available yet
21% of all live births	22% of all live births	23% of all live births	24% of all live births	25% of all live births	

Source: Virginia Department of Health, Center for Health Statistics, 109 Governor Street, Richmond, Virginia, 23219, 804-786-6206

10. **Complications of Pregnancy**

Information on complications of pregnancy, labor, and delivery is captured on birth certificates and the information then becomes part of Virginia's vital statistics.

Number of Complications of Pregnancy

	CY 1985	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
Unduplicated Count of Births with Complications	32,882	36,012	36,345	36,039	data are no longer reported this way - see following page for new breakdown- new breakdown does not include complications relating to pregnancy	not available yet
Complications Related to Pregnancy						
Hemorrhage in early pregnancy	301	265	155	213		
Placenta previa	273	301	337	283		
Premature separation of placenta	410	430	442	386		
Other and unspecified antepartum hemorrhage	499	408	360	383		
Pre-eclampsia and eclampsia	1,599	1,567	1,550	1,386		
Other and unspecified hypertension	1,956	2,174	1,960	2,046		
Excessive vomiting	108	106	82	95		
Early or threatened labor	1,719	1,863	2,090	2,164		
Prolonged pregnancy	172	178	181	81		
Edema or excessive weight gain	187	140	156	102		
Infections of genitourinary tract	1,292	1,592	1,325	1,208		
Other and unspecified complications of pregnancy	96	94	101	96		
Conditions during the puerperium	15	14	9	4		
Conditions in the Mother Complicating the Pregnancy						
Venereal disease	127	192	131	102		
Other infective and parasitic diseases	947	1,294	1,043	1,115		
Diabetes mellitus	937	1,226	1,417	1,455		
Anemia	834	1,096	952	875		
Phlebitis, thrombosis and other venous complications	47	46	44	41		
Obesity	311	383	435	345		
Injury during pregnancy	186	138	11	24		
Operation during pregnancy	49	63	54	56		
Other conditions in mother affecting pregnancy	1,724	1,875	1,907	2,046		

Events of Labor and Delivery

	CY 1989
Unduplicated Count Of Births With Events	31,213
Placenta previa	466
Abruptio placenta	558
Other excessive bleeding	510
Breech/malpresentation	3,530
Cephalopelvic disproportion	4,292
Meconium, moderate/heavy	11,066
Premature rupture of membrane	2,759
Febrile	1,328
Precipitous labor	3,922
Prolonged labor	775
Cord prolapse	240
Anesthetic complications	48
Other complications of labor and delivery	10,089
	32% of all live births

	CY 1985	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
Complications Affecting Delivery						
Multiple pregnancy	531	751	699	727		
Malposition or malpresentation of fetus	2,501	2,702	2,499	2,501		
Fetopelvic disproportion	3,304	3,296	3,324	2,891		
Uterine scar from previous surgery	4,794	5,163	5,480	5,486		
Cervical incompetence	166	174	154	167		
Other or unspecified abnormality of organs and soft tissues of pelvis	107	145	141	139		
RH incompatibility	337	368	353	323		
Fetal distress	5,108	6,433	6,441	5,998		
Other fetal and placental problems	319	425	453	476		
Polyhydramnios	75	102	70	75		
Premature rupture of membranes	1,660	1,698	1,609	1,709		
Other problems associated with amniotic cavity and membranes	460	566	488	484		
Obstructed labor	427	469	530	481		
Abnormality of forces of labor	2,293	2,632	2,469	2,678		
Prolonged labor	268	325	312	240		
Umbilical cord complications	3,609	4,372	4,560	4,089		
Perineal laceration	341	400	501	1,336		
Other obstetrical trauma	119	126	129	149		
Postpartum hemorrhage	172	191	182	183		
Retained placenta or membranes	160	222	174	232		
Other and unspecified complications of labor and delivery	385	467	544	588		
	38% of all live births	41% of all live births	40% of all live births	39% of all live births		

Source: Virginia Department of Health, Center for Health Statistics, 109 Governor Street, Richmond, Virginia, 23219, 804-786-6206

11. Pregnancy Losses

Information on pregnancy losses is captured on fetal death certificates and the information then becomes part of Virginia's vital statistics.

Number of Natural Fetal Deaths

	CY 1985	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
All Causes	6,995	7,397	7,201	7,896	data are no longer	not available
Causes and Conditions in Mother	890	1,239	1,015	1,179	reported this way - see following	yet
Hypertensive disorders	9	46	8	1	page for new break-	
Diseases or infections	2	10	1	1	down	
Injuries	0	2	0	3		
Other conditions unrelated to pregnancy	0	32	0	1		
Incompetent cervix	10	19	5	4		
Premature rupture of membranes	27	59	50	52		
Ectopic pregnancy	659	756	692	791		
Hydatidiform mole	16	26	24	21		
Blighted ovum	162	285	235	303		
Other complications	5	4	0	2		
Complications of Placenta, Cord and Membranes	162	317	192	238		
Placenta previa	7	10	4	0		
Other placental separation and hemorrhage	68	151	82	116		
Other abnormalities of placenta	34	36	25	31		
Placental transfusion syndrome	0	4	0	0		
Prolapsed cord	10	10	18	4		
Other compression of umbilical cord	22	52	54	74		
Other conditions of umbilical cord	17	36	9	1		

Number of Natural Fetal Deaths

	CY 1989
All Causes	7,785
Diseases of genitourinary system	15
Hydatidiform mole	27
Blighted ovum	389
Complications mainly related to pregnancy	24
Other indications for care in pregnancy, labor and delivery	32
Congenital anomalies	24
Maternal conditions which may be unrelated to present pregnancy	15
Incompetent cervix	18
Premature rupture of membranes	54
Ectopic pregnancy	885
Spontaneous abortion	3,895
Other placental separation and hemorrhage	146
Other abnormalities of placenta	12
Other and unspecified conditions of umbilical cord	107
Chorioamnionitis	34
Immaturity	97
Intrauterine hypoxia and asphyxia	27
Fetal hemorrhage	11
Hemolytic disease	3
Other, ill defined and unknown causes	1,970

	CY 1985	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
Abnormalities of membranes	4	18	0	0		
Chorioamnionitis	0	0	0	12		
Conditions in Fetus	193	228	182	247		
Immaturity	62	50	78	70		
Intrauterine hypoxia and birth asphyxia	95	59	65	112		
Congenital anomalies	28	95	37	53		
Other conditions in fetus	8	24	2	12		
Spontaneous Abortion	4,369	4,397	4,103	4,226		
Ill Defined and Unkown Causes	1,381	1,216	1,709	2,006		

Source: Virginia Department of Health, Center for Health Statistics, 109 Governor Street, Richmond, Virginia, 23219, 804-786-6206

12. **Alcohol Usage and Alcoholism Treatment Data**

Alcohol and drug usage data for women are not available. Alcoholism and drug treatment is provided by a number of public and private agencies and organizations. The one public agency that has the responsibility for alcoholism and drug treatment in Virginia is the Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services. Treatment services are provided through the local community services boards.

Number of Women Receiving Substance Abuse Treatment Services

FY 1985	FY 1986	FY 1987	FY 1988	FY 1989	FY 1990
not available	10,285	16,177	19,642	28,315	37,745

Source: Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services, Community Information Systems and Data Management, 109 Governor Street, Richmond, Virginia, 23219, 804-786-4148

13. **Utilization of Regional Neonatal Care Centers**

A number of hospitals in Virginia have specialized newborn intensive care nurseries. Six of these have been recognized as regional perinatal centers: Medical College of Virginia/VCU in Richmond, University of Virginia in Charlottesville, Children's Hospital of the King's Daughters and Sentara Norfolk General Hospital in Norfolk, Roanoke Memorial Hospital in Roanoke, Virginia Baptist Hospital in Lynchburg, and the Fairfax Hospital in Falls Church. There is no consistent method of data collection in these centers although the need to do so has been recognized. The Virginia Department of Health conducted a special survey in 1985 and determined that there are approximately 4,100 admissions annually to the six regional neonatal care centers. A special informal survey was done again for fiscal year 1990 and results were that there were 4009 admissions to the regional neonatal care centers.

Source: Virginia Department of Health, Division of Children's Specialty Services, Governor Street, Richmond, Virginia 23219, 804-371-4125

14. **Use of Trained Personnel for Completion of Birth Certificates**

In Virginia, it is the responsibility of hospitals to gather the information for birth certificates. This information may be gathered by various hospital personnel including medical records staff, ward clerks, etc. The demographic information is obtained from the mothers and the medical information is obtained from various medical records. Birth certificate information is sent from the hospitals through the local health departments to the Virginia Department of Health.

Training for personnel completing birth certificates is provided through courses in Virginia's Community College System as well as in-service training in the hospitals by the Virginia Department of Health. While most personnel are trained, there is no guarantee that all personnel completing birth certificates are trained. The Virginia Department of Health strives to keep birth certificates as simple as possible.

Source: Virginia Department of Health, Center for Health Statistics, 109 Governor Street, Richmond, Virginia, 23219, 804-786-6206

15. **Newborn Screening for Metabolic Disease**

Effective July 1, 1984, the Code of Virginia mandated that every infant be screened for the following: phenylketonuria (PKU), hypothyroidism, homocystinuria, galactosemia, and maple syrup urine disease (MSUD). The parent or guardian may refuse the performance of the test if there is conflict with religious practices. Prior to 1984, screening was being done for PKU and hypothyrodism. Screening for biotinidase deficiency was mandated in 1986 and for sickle cell disease (hemoglobinopathy) in 1989. The Division of Consolidated Laboratories, Department of General Services is responsible for screening. Coordination and assurance of appropriate and prompt follow-up of infants with suspected positive tests are the responsibility of the Division of Maternal and Child Health, Virginia Department of Health.

Number of Newborn Screenings for Metabolic Diseases

	CY 1985	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
Total screened (does not represent an unduplicated count)	102,001	105,948	110,310	114,873	114,570	114,914
			Diagnosed			
Phenylketonuria	4	4	6	4	4	4
Hypothyroidism	14	24	11	34	25	25
Galactosemia	0	2	4	2	1	1
Maple syrup urine disease	0	1	0	0	0	1
Homocystinuria	0	0	0	0	0	0
Biotinidase deficiency	not available	not available	0	0	2	0
Hemoglobinopathy	not available	not available	not available	not available	not available	70

Source: Virginia Department of Health, Division of Maternal and Child Health, 109 Governor Street, Richmond, Virginia, 23219, 804-786-7367

16. **Tracking System for High-Risk Infants**

For a number of years, Virginia has considered developing a high-risk infant tracking system. A study on a limited tracking system for high-risk infants discharged from the neonatal intensive care unit of the Medical College of Virginia to Richmond City (Project ACCESS) was carried out September 1988 - June 1989. Currently the High Priority Infant Monitoring Program is being piloted. This program is a joint effort between the Virginia Department of Health, the Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services (the lead agency for Public Law 99-457 Part H) and the Virginia Interagency Coordinating Council. The purpose of this program is to develop and implement a system to identify infants at risk for developmental delays; to screen for medical, developmental and environmental needs, to provide resource and referral information, to initiate appropriate referrals for services, and to assist families in obtaining services. The program is currently serving the Richmond City and Crater Health Districts with infants discharged from MCV/VCU, the Thomas Jefferson Health District with infants discharged from UVA, and the Norfolk and Eastern Shore Health Districts with infants from the Children's Hospital of the King's Daughters and Sentara Norfolk General Hospital. It is hoped that this program will be continued and expanded.

See also #22

Source: Virginia Department of Health, Division of Children's Specialty Services, 109 Governor Street, Richmond, Virginia, 23219, 804-371-4125

17. **Utilization of Infant Follow-up Programs**

There are no consistent data available in Virginia on infant follow-up programs for infants born with prematurity or multiple congenital anomaly syndromes. There was a special study conducted in 1985 by the Virginia Department of Health which indicated that approximately 25 percent of the high-risk neonatal intensive care graduates are enrolled in tertiary hospital follow-up programs. The High Priority Infant Monitoring Program should capture these type of data (see #16).

Source: Virginia Department of Health, Division of Children's Specialty Services, 109 Governor Street, Richmond, Virginia, 23219, 804-371-4125

18. **Neonatal Mortality Rate**

Information on neonatal mortality (deaths under 28 days) is captured on death certificates and information then becomes part of Virginia's vital statistics. Rate information is based on neonatal deaths per 1,000 live births.

Number and Rate of Neonatal Mortality

CY 1985	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
696	645	601	633	618	not available yet
rate 8.1	rate 7.4	rate 6.7	rate 6.8	rate 7.1	

Source: Virginia Department of Health, Center for Health Statistics, 109 Governor Street, Richmond, Virginia, 23219, 804-786-6206

19. **Infant Mortality Rate**

Information on infant mortality (deaths under one year) is captured on death certificates and information then becomes part of Virginia's vital statistics. Rate information is based on infant deaths per 1,000 live births.

Number and Rate of Infant Mortality

	CY 1985	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
Total	990	958	915	965	963	not available yet
	rate 11.5	rate 11.0	rate 10.1	rate 10.4	rate 10.0	
Certain gastrointestinal diseases	4	5	4	6	6	
Pneumonia and influenza	11	9	7	9	10	
Congenital anomalies	188	165	198	186	180	
Disorders relating to short gestation and low birth weight	123	117	93	115	175	
Birth trauma	2	5	6	2	7	
Intrauterine hypoxia and birth asphyxia	28	21	13	14	18	
Respiratory distress syndrome	79	66	51	56	61	
Other conditions originating in the perinatal period	301	288	268	292	266	
Sudden infant death syndrome	113	124	131	116	106	
All other causes	141	158	144	169	134	

Source: Virginia Department of Health, Center for Health Statistics, 109 Governor Street, Richmond, Virginia, 23219, 804-786-6206

20. **Low Birth Weight Rate**

Information on birth weight is captured on birth certificates and information then becomes part of Virginia's vital statistics. Rate information is based on low birth weight per 100 live births. Low birth weight is defined as weight less than 2500 grams.

Number and Rate of Low Birth Weight

CY 1985	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
6,070	6,207	6,355	6,628	6,941	not available yet
rate 7.1	rate 7.1	rate 7.0	rate 7.1	rate 7.2	

Source: Virginia Department of Health, Center for Health Statistics, 109 Governor Street, Richmond, Virginia, 23219, 804-786-6206

21. **Birth Defects Reported**

Information on birth defects is captured on birth certificates and information then becomes part of Virginia's vital statistics.

	Number of Congenital Anomalies					
	CY 1985	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
Total Anomalies Reported	789	789	689	638	data are no longer reported this way- see following page for new breakdown	not available yet
Anencephalus	10	12	9	7		
Spina bifida	34	29	22	22		
Other anomalies of nervous system	36	27	34	28		
Anomalies of eye	8	9	9	5		
Anomalies of ear, face, and neck	13	19	7	11		
Bulbus cordis anomalies and anomalies of cardiac septal closure	10	8	9	5		
Other anomalies of heart	42	43	28	29		
Other anomalies of circulatory system	13	16	9	11		
Anomalies of respiratory system	11	8	9	16		
Cleft palate and cleft lip	67	68	70	56		
Other anomalies of upper alimentary tract	12	10	12	7		
Other anomalies of digestive system	17	21	16	11		
Undescended testicle	15	20	25	24		
Hypospadias and epispadias	56	34	46	50		
Other anomalies of genitourinary system	47	42	36	38		
Congenital dislocation of hip	12	14	10	10		

Number Of Congenital Anomalies

	CY 1989
Total Anomalies Reported	1,792
Anencephalus	10
Spina bifida/meningocele	16
Microcephalus	3
Hydrocephalus	20
Other central nervous system anomalies	15
Heart malfunctions	73
Other circulatory/respiratory anomalies	136
Cleft lip/palate	83
Tracheo-esophageal fistula/esophageal atresia	8
Rectal atresia/stenosis	5
Other gastrointestinal anomalies	20
Malformed genitalia	41
Renal agenesis	7
Other urogenital anomalies	98
Clubfoot	45
Polydactyly/syndactyly/adactyly	120
Diaphragmatic hernia	11
Omphalocele/gastroschisis	21
Other musculoskeletal/integumental anomalies	123
Down syndrome	45
Other chromosomal anomalies	90
Other specified anomalies	802
Unduplicated count	1,609

	CY 1985	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
Deformities of feet	57	76	52	59		
Polydactyly	92	108	86	77		
Syndactyly	16	13	14	10		
Other anomalies of limbs	46	50	35	36		
Other anomalies of musculo-skeletal system	38	40	34	38		
Anomalies of the integument	40	43	46	36		
Down syndrome	38	45	28	25		
Other chromosomal anomalies	16	11	14	3		
Other and unspecified anomalies	43	23	29	25		
Unduplicated count	698	716	607	571		
	1% of all live births	1% of all live births	1% of all live births	1% of all live births		

Source: Virginia Department of Health, Center for Health Statistics, 109 Governor Street, Richmond, Virginia, 23219, 804-786-6206

22. **Diagnostic Information From Other Sources**

The Virginia Congenital Anomalies Reporting and Education System (Virginia CARES) was mandated effective January 1987 to 1) collect data in order to evaluate possible causes of birth defects for improved diagnosis and treatment; and 2) inform parents and physicians about resources available to assist children with birth defects. Data are extracted from birth certificates and report forms submitted by hospitals (see following page). To date 1987 data has been obtained from the system. Congenital anomalies are reported on birth certificates (see #21) but as the following data indicate there is obviously under-reporting.

The Virginia Hearing Impairment Identification and Monitoring System (Virginia HIIMS) was mandated effective October 1987 to identify and monitor children at risk of hearing impairments. Data are reported from all newborn nurseries and neonatal intensive care centers. From October 1, 1987 through July 31, 1989, 2,809 children were identified as being at risk. Hearing loss was confirmed for 13 children. For fiscal year 1990, 1,475 children were identified as being at risk. Hearing loss was confirmed by 13 children.

See also #36

Source: Virginia Department of Health, Division of Maternal and Child Health, 109 Governor Street, Richmond, Virginia, 23219, 804-786-7367

Comparison Between Birth Certificates and VaCARES*

Number of Congenital Anomalies	1987 VA Birth Certificates	VaCARES 1987 Birth Cohort
Anencephalus and similar anomalies	9	11
Spina bifida	22	58
Other anomalies of nervous system	34	176
Anomalies of eye	9	65
Anomalies of ear, face, and neck	7	133
Bulbus Cordis anom. and anom. of cardiac septal closr.	9	439
Other anomalies of heart	28	352
Other anomalies of circulatory system	9	491
Anomalies of respiratory system	9	141
Cleft palate and cleft lip	70	211
Other anomalies of upper alimentary trct.	12	160
Other anomalies of digestive system	16	164
Undescended testicle	25	211
Hypospadias and epispadias	46	252
Other anomalies of genitourinary system	36	105
Congenital dislocation of hip	10	136
Deformities of feet	52	227
Polydactyly	86	264
Syndactyly	14	58
Other anomalies of limbs	35	170
Other musculoskeletal anomalies	34	261
Anomalies of the integument	46	348
Down syndrome	28	65
Other chromosomal anomalies	14	48
Other and unspecified congenital anomalies	29	124
Total Anomalies	689	4,670

* Includes Virginia residents with Virginia birth certificates only

23. Enrollment in Early Intervention Programs

Early intervention programs for infant stimulation and training and support to families are offered by a number of public and private agencies. The Virginia Department of Education provides special education and related services to children and youth in need. These services are provided through local school divisions. For preschool services, the Department usually begins services at age three. Some services are provided to children under three. The Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services provides early intervention services to children in need from birth until three. These services are provided through local community services boards. Children can be transitioned out of early intervention services into special education services. Many other agencies provide early intervention services to children. The Department of Mental Health, Mental Retardation, and Substance Abuse Services captures the information on early intervention services.

Number of Children Receiving Special Education Services

Age	Dec. 1985	Dec. 1986	Dec. 1987	Dec. 1988	Dec. 1989	Dec. 1990
0-1	7	8	1	41	189	127
1	57	51	43	52	36	95
2	494	513	528	701	688	835
3	1,383	1,486	1,642	1,558	1,611	1,846
Total	1,941	2,058	2,214	2,352	2,524	2,903

Number of Children Receiving Early Intervention Services

	Dec. 1985	Dec. 1986	Dec. 1987	Dec. 1988	Dec. 1989	Dec. 1990
0-1	not available	not available	550	1,539	3,009	break-
1-2			882	1,841	4,120	out not
2-3			708	1,370	2,777	available
Total			2,140	4,750	9,906	10,419

Source: Virginia Department of Education, Information Systems Division, 101 North 14th Street, Richmond, Virginia, 23219, 804-225-2920

Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services, Early Intervention Programs, 109 Governor Street, 23219, 804-786-3710

24. **Developmental Screening Efforts**

Child Find is the responsibility of the Virginia Department of Education and is carried out by the local school divisions. The functions of Child Find are 1) to identify unserved children from birth to 21 who are in need of special services guaranteed to them by law; 2) to promote community awareness of handicapping conditions and involve the public in service delivery; and 3) to identify and define the infant and preschool population in need of services. There are no statewide data kept on Child Find.

Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) is a joint program of the Virginia Department of Medical Assistance Services and Virginia Department of Social Services. The Virginia Department of Medical Assistance Services funds EPSDT as part of Medicaid. The Virginia Department of Social Services through the local social services departments determines eligibility and makes arrangements for services which are provided by local health departments and private physicians.

Number of Children Screened for EPSDT

FY 1985	FY 1986	FY 1987	FY 1988	FY 1989	FY 1990
42,423	41,350	40,362	40,501	43,232	not available

Source: Virginia Department of Education, Information Systems Division, 101 North 14th Street, Richmond, Virginia, 23219, 804-225-2920

Virginia Department of Social Services, Bureau of Foster Care and Adoption Services, 8007 Discovery Drive, Richmond, Virginia, 23229, 804-662-9695

25. **Blood Lead Screening**

Screening for blood lead is the most common method of detecting environments which are potentially dangerous as a source of lead poisoning. In 1989, approximately 57,599 children were screened by local health departments for lead poisoning. Of these, 215 were identified with lead poisoning. This was a special survey.

Source: Virginia Department of Health, Division of Maternal and Child Health, 109 Governor Street, Richmond, Virginia, 23219, 804-786-7367

26. **Immunization Levels**

Adequate immunization to prevent disease is extremely important for infants and children and particularly for children entering child care facilities and schools. Adequate immunization is defined as three or more doses of oral polio vaccine, three or more shots of DPT (diphtheria/pertussis/tetanus) and one shot each of measles, mumps, and rubella. The Virginia Department of Health captures immunization information on licensed child care facilities, the Head Start Program, and school children (K - 1st grade).

Percent of Children Adequately Immunized in Licensed Child Care Facilities

Fall 1985	Fall 1986	Fall 1987	Fall 1988	Fall 1989	Fall 1990
95.8%	96.5%	95.3%	95.9%	95.3%	94.7%

Percent of Children Adequately Immunized in Head Start Programs

Fall 1985	Fall 1986	Fall 1987	Fall 1988	Fall 1989	Fall 1990
not available	95.4%	90.6%	91.7%	92.7%	94.7%

Percent of Students (K - 1st grade) Adequately Immunized

Fall 1985	Fall 1986	Fall 1987	Fall 1988	Fall 1989	Fall 1990
97.4%	97.5%	96.6%	96.2%	96.1%	97.2%

Source: Virginia Department of Health, Immunization Program, 109 Governor Street, Richmond, Virginia, 23219, 804-786-6246

27. **Percentage of Children with a Medical Home**

This is a concept that has been recommended in Virginia, but to date it has not been adopted. A medical home would provide a stable course of regular pediatric care and anticipating guidance.

Source: Virginia Department of Health, Division of Maternal and Child Health, 109 Governor Street, Richmond, Virginia, 23219, 804-876-7367

28. **Presence of Family Support Services**

Many public and private agencies and organizations provide support services to families of children with disabilities. The Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services has taken the lead in providing respite care to families of children with mental retardation. Even though respite care is not a mandated service, a number of local community services boards provide it.

Number of Children with Mental Retardation Receiving Respite Care

FY 1985	FY 1986	FY 1987	FY 1988	FY 1989	FY 1990
not available	72	35	33	60	58

The Virginia Institute for Developmental Disabilities (VIDD) has had a demonstration project on respite care for children with developmental disabilities. This project has had two model programs at several sites and will be expanded over the next three years.

Source: Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services, Community Information Systems and Data Management, 109 Governor Street, Richmond, Virginia, 23219, 804-786-4148

Virginia Institute for Developmental Disabilities, Virginia Commonwealth University, 301 West Franklin Street, Richmond, Virginia, 23284, 804-225-3876

29. **Childhood Mortality Rates**

Information on childhood mortality is captured on death certificates and information then becomes part of Virginia's vital statistics. Rate information on childhood mortality is not produced on a regular basis. Accidents, suicide, homicide, congenital anomalies, heart disease, and malignant neoplasms are the leading causes of death in children over one.

Number and Percent of Childhood Mortalities

	CY 1985	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
Diseases	1,196 (74%)	1,191 (73%)	1,144 (70%)	1,194 (73%)	1,192 (72%)	not
Accidents	306 (19%)	350 (21%)	362 (22%)	318 (19%)	317 (19%)	available
Suicides	58 (4%)	49 (3%)	68 (4%)	58 (4%)	58 (4%)	yet
Homicides and legal intervention	43 (3%)	49 (3%)	58 (4%)	59 (4%)	75 (4%)	
Other	4 (1%)	3 (1%)	8 (1%)	5 (1%)	7 (1%)	
Total	1,607	1,642	1,640	1,634	21,649	

Source: Virginia Department of Health, Center for Health Statistics, 109 Governor Street, Richmond, Virginia, 23219, 804-786-6206

30. **Studies on Malnutrition**

Poor nutrition continues to be a problem, particularly in the low income families. Low income infants and children often have low weight - for - height (wasted), low height - for - age (stunted), and are anemic. Infant malnutrition can contribute to developmental delays and possible mental retardation. The Women, Infant, and Children's Program (WIC) provides nutritional support to those eligible. The enrollment in this Program, however, is low. The Virginia Department of Health is responsible for the WIC Program. Services are delivered by the local health departments.

Number of Infants and Children Enrolled in WIC

	May 1985	Nov 1986	March 1987	March 1988	March 1989	March 1990
Low Weight for Height	3,814	not available	4,545	5,059	5,375	6,379
Low Height for Age	6,364		8,027	8,794	9,904	11,167
Anemia	8,593		8,673	8,755	8,943	9,174
Total	18,771		21,245	22,608	24,222	26,720
	38% of those enrolled		38% of those enrolled	37% of those enrolled	37% of those enrolled	36% of those enrolled

Source: Virginia Department of Health, WIC Program, 109 Governor Street, Richmond, Virginia, 23219, 804-786-5420

31. Childhood Accidents and Injuries

Injuries are the leading cause of disability in children. Brain injuries in particular can cause mental retardation and other developmental disabilities. The Virginia Department of Motor Vehicles captures information on motor vehicle injury. These injuries include pedestrians, bicyclists, and motorcyclists as well as other vehicles. The Virginia Department of Health is responsible for the Statewide Trauma Registry which was mandated by the General Assembly as of July 1987. The Statewide Trauma Registry collects data on injuries requiring admission to a hospital.

Number of Children Injured by Motor Vehicles

CY 1985	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
19,058	20,159	20,941	19,916	20,233	18,861

Number of Injuries of Children Requiring Hospital Admission

	CY 1985	CY 1986	CY 1987	CY 1988	CY 1989	CY 1990
Motor Vehicle	not available	not available	not available	2,105	not	not
Pedestrian				227	available	available
Bicycle				193	yet	yet
ATV				79		
Falls				1,175		
Burns				189		
Gunshot Wounds				113		
Assaults				91		
Stabs				54		
Lacerations				94		
Lawn Mower				24		
Back				2		
Total				4,346		

Source: Virginia Department of Motor Vehicles, 2300 West Broad Street, Richmond, Virginia, 23220, 804-367-1143

Virginia Department of Health, Division of Emergency Medical Services, 1538 East Parham Road, Richmond, Virginia, 23288, 804-371-3500

32. **Child Abuse and Neglect Data**

Large numbers of infants and children are abused and neglected by their parents and caretakers as well as other people. Abuse and neglect can cause developmental delays and possibly mental retardation. Infants and children who have disabilities are at particularly high-risk of being abused and neglected. The Virginia Department of Social Services is responsible for child protective services. The Department maintains a Central Registry of infants and children who have been abused and neglected. Child protective services are delivered by the local departments of social services.

Number of Child Abuse and Neglect Complaints and Cases

	FY 1985	FY 1986	FY 1987	FY 1988	FY 1989	FY 1990*
Complaints	49,765	47,888	47,931	50,228	52,759	43,341
Founded/Reason to Suspect Cases	12,213	11,583	11,052	11,342	12,072	12,129
Physical Neglect	45.4%	44.3%	44.1%	45.1%	46.8%	51.4%
Sexual Abuse	12.7%	13.3%	14.4%	13.8%	12.4%	11.8%
Physical Abuse	16.2%	17.9%	17.6%	17.7%	20.2%	20.4%
Other	25.6%	24.5%	23.8%	23.3%	20.5%	16.4%

* New computer system went into effect causing some differences in reporting.

Source: Virginia Department of Social Services, Bureau of Child Protective Services, 8007 Discovery Drive, Richmond, Virginia, 23229, 804-662-9081

33. **Out-of-Home Placements**

When the situation arises that requires an infant or child to be removed from his/her home and placed somewhere else, it is likely that the child is at risk of developmental delays/disabilities or already has developmental delays/disabilities. There are a number of agencies and organizations in Virginia that make foster home and adoptive home placements. The Virginia Department of Social Services is the one public agency that is responsible for foster care and adoption. Foster care and adoption services are delivered by the local departments of social services.

Number of Children in Foster Care

June 1985	June 1986	June 1987	June 1988	June 1989	June 1990
6,101	5,810	5,773	5,863	5,992	6,217
7% of these are in adoptive homes	7% of these are in adoptive homes	7% of these are in adoptive homes	7% of these are in adoptive homes	7% of these are in adoptive homes	7% of these are in adoptive homes

Source: Virginia Department of Social Services, Bureau of Foster Care and Adoption Services, 8007 Discovery Drive, Richmond, Virginia, 23229, 804-662-9695

34. **Special Surveys and/or Census**

The Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services provides services to children with mental retardation through local community services boards. This is just one statewide census.

Number of Children Receiving Mental Retardation Services

	FY 1985	FY 1986	FY 1987	FY 1988	FY 1989	FY 1990
Emergency	not available	0	17	12	23	5
Outpatient		not available	not available	204	80	173
Case Management		1,916	2,139	979	1,652	1,717
Sheltered Employment		279	238	20	40	22
Education/Recreation		1,315	1,302	1,190	1,260	1,283
Supported Employment		138	179	7	17	11
Alternative Day Support		0	0	125	347	306
ICF/MR		9	24	0	32	0
Group Homes		45	28	7	7	12
Supervised Apartments		12	19	1	2	0
Domiciliary Care		0	3	0	0	0
Residential Respite		72	35	33	60	58
Sponsored Placements		19	24	12	9	11
Supported Living Arrangement		305	410	591	608	624
Early Intervention		2,167	2,569	2,867	3,467	4,099
Total		6,277	6,987	6,048	7,604	8,321

Source: Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services, Community Information Systems and Data Management, 109 Governor Street, Richmond, Virginia, 23219, 804-786-4148

35. **Reporting by State Department of Education**

The Virginia Department of Education provides special education and related services to handicapped children and youth. These services are provided through local school divisions.

Number of Children and Youth Receiving Special Education Services

	Dec. 1985	Dec. 1986	Dec. 1987	Dec. 1988	Dec. 1989	Dec. 1990
Educable Mentally Retarded	10,775	10,136	9,785	9,426	9,039	8,841
Trainable Mentally Retarded	2,941	2,845	2,798	2,762	2,685	2,656
Severely and Profoundly Handicapped	809	925	942	1,099	1,111	1,166
Hard of Hearing	698	691	756	729	717	763
Deaf	349	387	288	384	431	394
Speech or Language Impaired	28,977	28,568	28,599	27,779	27,149	28,548
Visually Handicapped	130	164	139	101	153	159
Seriously Emotionally Disturbed	6,990	7,051	7,352	7,669	7,788	8,436
Orthopedically Impaired	630	677	674	755	779	792
Other Health Impaired	171	207	222	219	300	403
Autistic	207	230	283	324	411	480
Specific Learning Disabled	44,969	46,153	48,548	49,548	50,538	53,115
Deaf-Blind	7	3	3	4	6	5
Multihandicapped	1,320	1,179	1,178	855	856	1,013
Developmentally Delayed	2,544	2,761	2,944	3,642	3,895	4,006
Total	101,517	101,977	104,511	105,296	105,858	110,777

Source: Virginia Department of Education, Information Systems Division, 101 North 14th Street, Richmond, Virginia, 23219, 804-225-2920

36. Information from Centers and Interest Groups

There are a number of centers and interest groups in Virginia that work with people with disabilities and their families. The Virginia Department of Health is responsible for children's specialty services which are provided by local health departments. The Virginia Department of Health is also responsible for child development clinics. There are 13 of these clinics statewide which serve children suspected of developmental and behavioral disorders.

Number of Patients Receiving Children's Specialty Services

	FY 1985	FY 1986	FY 1987	FY 1988	FY 1989	FY 1990
*Adult cystic fibrosis	48			1	62	72
Cystic fibrosis	240	305	286	307	289	281
*Adult hemophilia	31	65	54	46	62	52
Hemophilia	51	71	62	67	86	93
*Adult neurology	322	30	390	373	370	306
Child neuroloyy	1,487	1,982	1,725	1,755	1,562	1,396
Diabetes			40	97	109	187
Endocrinology	30	51	74	119	167	122
Eye surgery	1,054	1,395	1,150	1,185	1,220	1,241
Facial deformity	333	393	284	299	307	315
Orthodontics/dental			200	205	213	209
Hearing impairment	2,058	2,263	2,197	2,003	2,011	2,072
MCV neuro/neurosurgery	60					
Orthopedic	4,419	4,514	3,364	3,385	3,183	3,023
Amputee			62	84	72	63
Cerebral palsy			551	619	551	553
Scoliosis			363	299	219	167
Muscular dystrophy			35	35	33	32
Spina bifida/mylo.			236	255	244	274
Pediatric cardiology	1,705	1,673	1,599	1,563	1,500	1,590
Pediatric neurosurgery	316	382	394	400	356	320
Pediatric surgery	134	94	134	146	144	112
Pediatric urology	484	540	555	590	528	556
Physical therapy			739	408	377	475
Plastic surgery	259	242	291	250	265	221
Primary care	not available	not available	not available	not available	not available	234
Rheumatoid arthritis	16	25	39	68	67	80
Sickle cell	0	1	1	13	5	7
Total	13,047	14,026	14,825	14,572	14,002	14,053

* The General Assembly mandated these three groups continue to be served after they turn 18.

Number of Children Served By Child Development Clinics by Primary Diagnosis

	FY 1985	FY 1986	FY 1987	FY 1988	FY 1989	FY 1990
Total Services	3,932	5,063	5,566	6,282	5,630	data are no longer reported this way - see following page for new breakdown
Primary Diagnosis						
Schizophrenic disorder	0	3	2	3	1	
Affective disorder	1	1	5	10	13	
Paranoid state	0	0	0	0	0	
Other nonorganic psychosis	0	0	1	0	0	
Psychosis with Origin specific to childhood	16	10	23	19	24	
Neurotic disorder	20	18	21	37	24	
Paranoid personality disorder	17	14	14	12	6	
Sexual deviations and disorders	5	0	1	1	0	
Drug dependence	0	0	0	1	0	
Non dependent abuse of drugs	1	2	0	0	0	
Physiological malfunction arising from alcohol abuse	0	0	0	0	0	
Special symptoms or syndromes	3	1	3	0	0	
Anorexia nervosa	2	0	1	0	1	
Tics	1	1	0	4	1	
Stereotyped repetitive movement	1	1	1	0	1	
Specific disorders of sleep of nonorganic origin	0	0	2	1	2	
Other and unspecified disorders of eating	0	0	0	1	1	
Enuresis	6	5	4	1	0	
Encopresis	4	4	8	6	3	
Psycholgia	1	0	0	0	0	

Number of Children Served by Child Development Clinics by Primary Diagnosis

	FY 1990
Total Services	8,154
Primary Diagnosis	
Schizophrenic disorder	0
Affective disorders	4
Paranoid state	0
Other nonorganic psychosis	0
Psychosis with origin specific to childhood	24
Neurotic disorder	13
Personality disorder	4
Sexual deviations and disorders	1
Substance abuse	1
Special symptoms or syndromes	4
Anorexia nervosa	0
Movement disorders	2
Specific disorders of sleep of nonorganic origin	1
Other and unspecified disorders of eating	0
Enurosis/encopresis	4
Psycholgia	0
Other and unspecified special symptoms and syndromes	0
Adjustment reaction	235
Specific nonpsychotic disorders due to mental disorders	0
Depressive disorder	4
Disturbance of conduct	79
Disturbance of emotions specific to childhood and adolescence	180
Hyperkinetic syndrome of childhood	612
Developmental disorders	880
Psychological factors associated with physical conditions	0
Mental retardation	220
Central nervous system/peripheral nervous system disorders	115
Musculo-skeletal system disorder and connective tissue disorder	9
Congenital anomalies	59
V-Diagnosis	135
Other conditions	178
Perinatal disorders	27
Infections neoplasms and metabolic disorders	18

	FY 1985	FY 1986	FY 1987	FY 1988	FY 1989	FY 1990
Other and unspecified syndromes	0	0	1	1	0	
Acute reaction to stress	17	15	4	6	3	
Adjustment reaction	305	317	348	319	203	
Specific nonpsychotic disorders due to mental disorders	2	0	2	6	2	
Depressive disorder	0	2	10	8	7	
Disturbance of conduct	98	125	85	108	65	
Disturbance of emotions specific to childhood and adolescence	132	134	119	204	227	
Hyperkinetic syndrome of childhood	233	288	373	498	588	
Developmental reading disorder	289	342	307	278	277	
Developmental speech/language disorder	196	300	306	288	275	
Coordination disorder	0	13	13	15	14	
Other developmental disorders	0	359	320	323	257	
Psychological factors associated with physical conditions	1	0	0	0	0	
Mental retardation - mild	148	154	126	199	122	
Mental retardation - moderate	95	81	69	95	69	
Mental retardation - unspecified	4					
Nervous system disorder	1	1	0	1	5	
Cerebral degeneration - child	2	3	2	3	5	
Other disorders of central nervous system	30	50	71	53	80	
Other disorders of peripheral nervous system	2	1	2	3	3	
Eye and vision disorder	14	8	6	12	3	
Ear and hearing disorder	3	8	9	48	26	
Musculo-skeletal system disorder and connective tissue disorder	3	2	2	3	6	
Congenital anomalies	44	55	46	63	48	
V-Diagnosis	65	103	147	209	105	

Source: Virginia Department of Health, Children's Specialty Services, 109 Governor Street, Richmond, Virginia, 23219, 804-786-3691

37. **SSI Disability Determinations**

Low-income infants and children who are disabled are eligible to receive Supplemental Security Income (P.L. 92-603, Social Security Act).

Number of Children Receiving Supplemental Security Income

Dec. 1985	Dec. 1986	Dec. 1987	Dec. 1988	Dec. 1989	Dec. 1990
4,856	5,006	5,102	5,216	5,258	not available yet
3% of these are blind	3% of these are blind	3% of these are blind	3% of these are blind	3% of these are blind	

Source: U.S. Department of Health and Human Services, Social Security Administration Office of Research and Statistics, 4301 Connecticut Avenue, N.W., Washington, D.C., 20008

38. **Medicaid, Insurance, and HMO Data Bases**

The Virginia Department of Medical Assistance Services is the state agency that is responsible for Medicaid. There are many private companies that provide insurance and HMO.

Number of Children Receiving Medicaid Services

	FY 1985	FY 1986	FY 1987	FY 1988	FY 1989	FY 1990
Categorically needy receiving maintenance	115,855	133,393	112,171	106,808	105,847	107,324
Categorically needy not receiving maintenance	2,006	6,084	4,474	12,161	13,734	not available
Medically needy	8,273	5,164	8,271	8,022	7,342	7,513
Other coverage groups created by legislation passed prior to 1988	not available	not available	not available	not available	not available	41,475
Total	126,134	144,641	124,916	126,991	126,923	156,312

Source: Virginia Department of Medical Assistance Services, 600 East Broad Street, Richmond, Virginia, 23219, 804-371-7562

39. **Establishment of Data Systems for Services**

State agencies have a number of data systems for services but they are not all client specific. There are a number of data systems which need to be revised and others which need to be developed. These needs have been identified by state agencies but often resources have not been available to meet the needs.

Source: See all other sources

40. In-service Education Activities for Service Providers

State agencies provide in-service to their own personnel. State organizations also provide education activities to their membership. More efforts are being made between state agencies and organizations to encourage multiagency/multiorganization education activities. The Virginia Institute for Developmental Disabilities at Virginia Commonwealth University is a university affiliated program which has as a goal interdisciplinary training and education. The Institute offers a number of interdisciplinary inservice training and education activities including the area of prevention.

Source: See all other sources

41. **Standards for Early Childhood Services**

The Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services is the lead agency for implementing P.L. 99-457, Part H (Early Intervention Program for Handicapped Infants and Toddlers). The Virginia Interagency Coordinating Council (VICC) has been established to work with the lead agency. VICC has a personnel subcommittee which is responsible for developing personnel standards and an administrative/legislative committee which is responsible for issues around supervision and monitoring programs.

The Virginia Council on Child Day Care and Early Childhood Programs was mandated by the General Assembly to become operational on July 1, 1989. The Council addresses planning, development and evaluation of child care and early childhood programs in Virginia. One emphasis is on at risk four year olds.

Source: Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services, Early Intervention Program, 109 Governor Street, Richmond, Virginia, 23219, 804-786-3710

Virginia Council on Child Day Care and Early Childhood Programs, 1100 Bank Street, Richmond, Virginia, 23219, 804-371-8603

42. **Use of Family Life Curricula in Schools**

The General Assembly mandated that there be family life education in all grades (K-10 or 12) in Virginia by September 1, 1990. It further mandated that Individual Education Plans for special needs students include family life education. Standards of learning and learning objectives were provided to the local school divisions to guide them in their curricula development.

Source: Virginia Department of Education, 101 North 14th Street, Richmond, Virginia, 23219, 804-225-3488

43. Efforts in Education of the Public

State agencies and organizations have numerous activities underway to educate the public about developmental disabilities and their prevention. These include presentations to groups such as businesses, organizations, agencies, the General Assembly; media releases; fund-raising campaigns; etc. In January of 1990, Action for Prevention, Inc. presented to the General Assembly a document that it had prepared in conjunction with the Virginia Institute for Developmental Disabilities and 140 professionals and advocates - Invest In Virginia's Future..... Prevent Developmental Disabilities - An Action Agenda for the 1990's.

Source: See all other sources

Other Data (complete with your own)

PRIMARY PREVENTION OF DEVELOPMENTAL DISABILITIES

VIRGINIA PROGRAMS AND PROJECTS

Overview

In the spring of 1991, the Virginia Institute for Developmental Disabilities sent out a survey requesting information on programs/projects in the State on prevention of developmental disabilities. Surveys were sent to the 40 local community services boards since they are responsible for prevention and treatment services for developmental disabilities and to selected state agencies and organizations known to have programs/projects on prevention of developmental disabilities. Many other state and local agencies and organizations have prevention programs/projects on developmental disabilities.

The 33 surveys that were returned are summarized on the following pages. Information includes name and phone number of a contact person for each program/project. The programs/projects are broken into the categories of:

1. prior to and during pregnancy
2. infancy/childhood/adolescence
3. both

At the end of the chapter is a blank form and instructions for completion. Please make copies of this form and complete for programs/projects that you are responsible for. This information will be disseminated to people who have these manuals.

Prior To And During Pregnancy
Prevention Programs/Projects

A Good Start Lasts A Lifetime, Prevent Premature Labor

Target Population: Medical/education field (doctors, nurses, midwives, hospitals, etc.)

Agency Responsible For This Program: Virginia Perinatal Association

City/County Where This Program Takes Place: Statewide (with occasional requests from other states)

Program Contact Person: Lisa Lee-High, Office Administrator

Program Telephone Number: (804) 353-4214

Brief Description of the Program: The brochure, videotape, and poster on "A Good Start Lasts A Lifetime, Prevent Premature Labor" is designed as a widely targeted educational intervention program to prevent premature labor.

Babies & You: A Worksite Prenatal Education Program

Target Population: Men and women of childbearing age; employers; worksite supervisors

Agency Responsible For This Program: March of Dimes Birth Defects Foundation

City/County Where This Program Takes Place: This is a national March of Dimes program, and is being implemented through each chapter in Virginia

Program Contact Person: Debbie Teeter, Richmond area

Program Telephone Number: (804) 353-9108

Brief Description of the Program: Babies & You takes prenatal education into the work place, where it is easier to reach people with important health information. The program is ideally planned around a series of seminars and addresses such Issues as: substance abuse, prenatal care, genetics, maternal nutrition, teen pregnancy, and low birth weight. The program is a free service of the March of Dimes.

Better Beginnings for Virginia's Children

Target Population: Adolescents

Agency Responsible For This Program: Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services

City/County Where This Program Takes Place: 38 cities/counties in Virginia

Program Contact Person: Susan Geller

Program Telephone Number: (804) 786-1530

Brief Description of the Program: Better Beginnings currently funds minigrants to 18 broad-based community coalitions to conduct a thorough local needs assessment regarding the prevention of adolescent pregnancy. Each coalition develops a five year strategic plan of action outlining goals and objectives to achieve based on data from the needs assessment. The State Better Beginnings Office provides training and technical assistance to the coalitions.

BRIDGES

Target Population: Teen mothers up to age 22

Agency Responsible For This Program: Prince William County Department of Social Services

City/County Where This Program Takes Place: Prince William Area

Program Contact Person: Ellen Chang

Program Telephone Number: (703) 335-7500

Brief Description of the Program: Program components involve case management, support, education, and advocacy of teen pregnancy prevention. Child care and transportation are provided to participants. Educational programs are conducted with assistance of Prince William County Health, Prince William County Community Services Board, and Prince William County School System.

Drugs and You

Target Population: Mentally retarded adults who are of child-bearing age and who are capable of living independently

Agency Responsible For This Program: Central Virginia Community Services, Prevention Division

City/County Where This Program Takes Place: Counties of Amherst, Appomattox, Bedford, and Campbell and Cities of Bedford and Lynchburg.

Program Contact Person: David A. Taylor

Program Telephone Number: (804) 847-8050

Brief Description of the Program: Drugs and You is a substance abuse prevention program and Fetal Alcohol Syndrome prevention program designed for the mentally retarded adult. It is ten one-hour sessions that provide information on chemical abuse, dangers associated with chemical abuse, and refusal techniques. The program is based on the curriculum Life Facts 3: Substance Abuse.

High Risk Pregnancy Intervention Program

Target Population: Pregnant women (any age) primarily in South Norfolk Borough of Chesapeake, others served as needed

Agency Responsible For This Program: Substance Abuse, Chesapeake Community Services Board

City/County Where This Program Takes Place: Chesapeake

Program Contact Person: Ann Roach

Program Telephone Number: (804) 543-4262

Brief Description of the Program: **Purpose:** To ensure a healthy baby through elimination of harmful drugs during pregnancy especially nicotine, alcohol, and illegal drugs. **Services:** Holistic counseling, collaborative home visits, groups to promote mutual concerns and shared interest of mothers, transportation, and networking to secure resources. **Goals:** To help pregnant women recognize and deal with the harmful effects of drug abuse, to offer confidential support so that the pregnant woman can choose to make a lifestyle change, to refer to treatment, and provide appropriate services to facilitate the bonding between "Healthy Mothers and Healthy Babies".

Project Alpha: Man-to-Man Talk About Teenage Pregnancy

Target Population: Adolescent males

Agency Responsible For This Program: March of Dimes Birth Defects Foundation

City/County Where This Program Takes Place: This is a national March of Dimes program; each Virginia chapter has the ability to implement

Program Contact Person: Debbie Teeter, Richmond area

Program Telephone Number: (804) 353-9108

Brief Description of the Program: This program was designed in partnership between the March of Dimes and the Alpha Phi Alpha Fraternity. Fraternity members, acting as March of Dimes volunteers, lead sessions that explore the problems of teen pregnancy from the male perspective. Programs offered around the Richmond area to date have been well-received and well-implemented by fraternity members.

Infancy/Childhood/Adolescence
Prevention Programs/Projects

Coping with Stressors as a Parent

Target Population: Women in our shelter for battered women and women in a transitional program sponsored by the battered women's shelter

Agency Responsible For This Program: Portsmouth Community Services Board

City/County Where This Program Takes Place: Portsmouth

Program Contact Person: Candice Anglin

Program Telephone Number: (804) 383-8618

Brief Description of the Program: Identification of stressors and things beyond our control, physical effects of stress, the stress of remedial parenting, how we tend to revert to familiar patterns of behavior even when they are negative, and stress management are dealt with in this program.

Crater District Infant Intervention Program

Target Population: High risk infants

Agency Responsible For This Program: Infant Programs, District 19 Community Services Board

City/County Where This Program Takes Place: Crater District covers nine localities including: Petersburg, Hopewell, Dinwiddie, Prince George, Sussex, Surry, Emporia, Colonial Heights, and Greenville

Program Contact Person: Carol Webster, Director of MR Services

Program Telephone Number: (804) 862-9940

Brief Description of the Program: Infants and toddlers that are referred to the infant program who do not qualify for direct therapy services (occupational therapy, physical therapy, speech or education) are placed on the monitor registry. These infants are screened developmentally at three, six and 12 month intervals. At the time of screening, parents receive information on child development, behavior management, nutrition, and other information as needed. Individualized activities to stimulate development are also given to parents. Some babies need more frequent monitoring and some parents receive more intensive parent training. Parent-child interaction groups are held periodically for this group .of families. This group focuses on basic interaction skills, cue readings, handling toddler behaviors, structuring the child's day, selecting and making appropriate toys, nutrition and safety, etc.

This monitoring program is very flexible and designed to meet individual family and child needs. Children are screened at two years of age and referred to the school system if needed. Those who do not receive preschool services at age two (and at a very high risk for learning problems) are again screened at age three to determine need for re-referral to the school system.

Crossroads Infant Intervention Program

Target Population: Developmentally delayed and at risk infants ages birth through two years

Agency Responsible For This Program: Crossroads Services Board

City/County Where This Program Takes Place: Piedmont Planning District 14 (Amelia, Buckingham, Charlotte, Cumberland, Lunenburg, Nottoway, and Prince Edward)

Program Contact Person: Belinda M. Gee

Program Telephone Number: (804) 392-8502

Brief Description of the Program: Home-based program with the parent or caretaker designated as the primary teacher. Services provided: (1) Assessment/Testing - assessment teams evaluate the child's development and formulate Individual Family Service Plan; (2) Home Visits - made on an as needed basis to assist the parent with increasing developmental skills; (3) Family to Family Support Group - provides assistance to families with children who have special health or developmental needs; (4) Physical Therapy - treatment for children with delays in their fine and/or gross motor skills; and (5) Parenting Groups - target population is teenage parents and parents who lack the appropriate skills to provide a wholesome and stimulating environment for their children. These groups have been coordinated with local high schools and social service agencies.

Early Intervention Program

Target Population: Infants (birth to two years of age) who may be at risk for possible developmental delays

Agency Responsible For This Program: Washington County Schools

City/County Where This Program Takes Place: Washington County and Bristol City

Program Contact Person: Ellen Hammond

Program Telephone Number: (703) 628-1896

Brief Description of the Program: A home-based program was developed to serve infants and families in the Washington County/Bristol, Virginia area who have special needs. This program is operated by Washington County Schools, Bristol City Schools, and Highlands Community Services at no cost to the residents of these areas.

The program assists parents in learning how to work effectively with their infant. Staff can assist parents in teaching their child everyday skills such as feeding, crawling, walking, talking, playing, and social interaction.

The Early Intervention Program can also assist family members in understanding the difficulties and concerns that are associated with a special needs infant. It is important to know that family members can be the best teacher when a special needs child is faced with growth and development difficulties.

Services are provided through home visits as needed for the child and family. Parents are assisted in ways to encourage and help in the child's growth and development. Additional services are available if the need exists such as physical therapy, speech and language therapy, and occupational therapy.

An Individualized Family Services Plan is developed in order to meet the needs of the infant as well as the family. Each child is assessed in the following areas:

- receptive/expressive language
- cognitive learning
- social/emotional skills
- self-help skills
- gross motor development
- fine motor development

Each assessment is repeated every four to six months in order to evaluate the child's progress.

Halifax County Community Action - Infant Development and Parent Education Services

Target Population: Infants and toddlers - birth to two years old with a handicapping condition, developmentally delayed or "at risk"

Agency Responsible For This Program: Southside Community Services Board contracting to Halifax County Community Action, Inc.

City/County Where This Program Takes Place: Counties of Halifax, Mecklenburg, and Brunswick and the City of South Boston

Program Contact Person: Jacquelyn F. Moody

Program Telephone Number: (804) 575-6916

Brief Description of the Program: The Infant Development and Parent Education Services serves children from birth to two years of age with handicapping conditions, developmentally delays, or the "at risk" residing in the counties of Mecklenburg, Brunswick, Halifax and the City of South Boston.

LIFT

Target Population: Developmentally delayed or at risk for delay infants (birth through age 2 years) and their families

Agency Responsible For This Program: Valley Community Services Board

City/County Where This Program Takes Place: Staunton, Waynesboro, Augusta, and Highland County

Program Contact Person: Paula Kaiser

Program Telephone Number: (703) 943-6604, or 886-1989

Brief Description of the Program: Program includes developmental assessment, infant education, physical therapy, speech and language therapy, service coordination, parent-to-parent support, information, and referral. Mission - prevent or minimize later developmental delay.

Mother's Group

Target Population: Mothers who have a delay and/or have some parenting concerns and delayed children

Agency Responsible For This Program: Virginia Beach Community Services Board

City/County Where This Program Takes Place: Virginia Beach

Program Contact Person: Libba Hill

Program Telephone Number: (804) 473-5223

Brief Description of the Program: Mothers meet once a week for fun, sharing, parenting skills, group discussing, budgeting, etc. Children meet at the same time for play activities, structure.

PACE (Parent and Child Education)

Target Population: Developmentally delayed, handicapped, and high-risk infants, birth to two years old

Agency Responsible For This Program: Harrisonburg-Rockingham Community Services Board

City/County Where This Program Takes Place: Harrisonburg and Rockingham

Program Contact Person: Anne Callahan

Program Telephone Number: (703) 434-1941

Brief Description of the Program: PACE is an early intervention program serving delayed, handicapped, and at risk infants birth to two years of age and their families. Services are primarily home based. Parents are trained to teach their own children. Services provided may include: physical therapy, speech therapy and education.

Parent Infant Education Program (PIE)

Target Population: Infants, toddlers (birth to two years of age) with disabilities and their families

Agency Responsible For This Program: Department of Human Services, Mental Health and Substance Abuse Division

City/County Where This Program Takes Place: Arlington County

Program Contact Person: Alma McPherson

Program Telephone Number: (703) 358-4965

Brief Description of the Program: The PIE Program provides therapeutic and educational services to infants with developmental delays or special needs. PIE works with parents to help each child develop his/her capabilities. There is a monthly charge for services based on a sliding scale. No Arlington family will be denied services because of inability to pay.

Parenting Education Program (Prevention Services)

Target Population: Parents with child birth to five years and prenatal teenagers

Agency Responsible For This Program: Allegheny Highlands Community Services Board

City/County Where This Program Takes Place: Allegheny County, Cities of Clifton Forge and Covington

Program Contact Person: Debbie Taylor

Program Telephone Number: (703) 862-1714

Brief Description of the Program: Program is home-based, intense services (see clients at least weekly) including assessments, treatment plans, case management, teach parenting skills. The program will include group work in near future.

PLEASE BE SEATED

Target Population: Parents and other individuals who transport children under the age of four and 40 pounds who are not properly secured in a child safety seat

Agency Responsible For This Program: Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services

City/County Where This Program Takes Place: Statewide

Program Contact Person: Karen C. Kern

Program Telephone Number: (804) 786-5993 or 786-5507

Brief Description of the Program: PLEASE BE SEATED enlists the assistance of citizens to educate non-users of child safety seats for young children. Citizens who observe children under the age of four not properly restrained while in a moving vehicle can now do something about it.

The program consists of a system whereby individuals who observe safety seat violations can fill out and mail a postage paid card to the Department for Mental Health, Mental Retardation, and Substance Abuse Services. The owner of the identified vehicle is sent a friendly reminder letter from the Department for Mental Health, Mental Retardation, and Substance Abuse Services, educational materials, and information on free safety seats available to qualified low income families.

The PLEASE BE SEATED mail-in cards are available at pediatricians' offices, Virginia Cooperative Extension Offices, rescue squads, AAA branches, and Division of Motor Vehicles branch offices.

Positive Parenting

Target Population: Women in our shelter for battered women and women in a transitional program sponsored by the battered women's shelter

Agency Responsible For This Program: Portsmouth Community Services Board

City/County Where This Program Takes Place: Portsmouth

Program Contact Person: Candice Anglin

Program Telephone Number: (804) 393-8618

Brief Description of the Program: Goals of misbehavior, communication skills activities, alternatives to physical and verbal punishment, and skill building activities are dealt with in this program.

Project ESI

Target Population: Available for Chesterfield Health Department, Chesterfield-Colonial Heights Social Services, and one pediatrician's office

Agency Responsible For This Program: Chesterfield County Community Services Board

City/County Where This Program Takes Place: Chesterfield County

Program Contact Person: Carol Granger

Program Telephone Number: (804) 271-4871

Brief Description of the Program: Project ESI (Early Screening of Infants) is a program offered by the Chesterfield Infant Program to provide early identification for possible delays in development for children birth through age two. It is the intent of this program to assist the physician or agency in providing services to families. A developmental screening will be provided free to the child recommended by the physician or agency. When necessary, specific suggestions will be provided to the family to reinforce previous discussions either in a booklet or written form. The screener with recommendations will be left with the physician or agency. A follow-up contact is available.

Children who would be appropriate for referral would include:

- Children older than 15 months who are delayed in walking for no apparent physical reason
- Children whose quality of movement is at question; i.e., poor muscle tone, floppy with no specific diagnosis
- Children who have problems feeding or their intake is compromised with no apparent physical reason
- Repeated chronic otitis media for one year's duration
- Infants who appear to have poor attachment or interaction with primary caregiver
- Children at 18 months of age who parents report use few, if any, words and mainly grunt and point to have needs and wants taken care of
- Children whose skills are occurring out of sequence (e.g.; crawling without sitting, walking without crawling)
- Babies who failed crib-o-gram test with no audiological report

Also, children with a diagnosed physical or mental condition which has a high probability of resulting in a developmental delay (to include, but not limited to, Down Syndrome or other chromosomal abnormalities, spina bifida, meningitis, birth asphyxia at five minutes

with an apgar less than seven or a need to receive continuous resuscitation after five minutes, intracranial hemorrhage and/or seizures, and confirmed congenital metabolic disorder).

Project Impact

Target Population: Birth through two years with handicapping conditions, developmental delays, or "at risk" for delay

Agency Responsible For This Program: Allegheny Highlands Community Services Board

City/County Where This Program Takes Place: Cities of Covington and Clifton Forge and Allegheny County

Program Contact Person: Hazel Lawler

Program Telephone Number: (703) 862-1714

Brief Description of the Program: This is an early intervention program for families of children with special needs. The program includes developmental screening, assessment, and programming services home-based with limited center-based component.

Protect Our PreSchoolers (POPS)

Target Population: Pre-school children (2 to 5 years) and their parents

Agency Responsible For This Program: Virginia Beach Community Services Board

City/County Where This Program Takes Place: Virginia Beach

Program Contact Person: Georgeane Blumling

Program Telephone Number: (804) 473-5223/340-6851

Brief Description of the Program: This is a traffic education program teaching pedestrian and passenger safety. Program is in kit form and teachers are trained to use the kit. Program length varies with the age of the children. Multiple activities included, parent education also insured.

Regional Child Development Center

Target Population: Infants and toddlers birth through two, at risk, with developmental delay or identified handicap, and their families

Agency Responsible For This Program: Developmental Services, Inc., Big Stone Gap

City/County Where This Program Takes Place: Lee, Scott, Wise Counties and the City of Norton

Program Contact Person: Karen Davis

Program Telephone Number: (703) 523-0682

Brief Description of the Program: RCDC can: Test the baby, teach the baby, teach parents special ways to help the baby grow, and work with parent and their baby regardless of their income.

The Nurturing Program

Target Population: Teen mothers

Agency Responsible For This Program: New River Valley Community Services Board

City/County Where This Program Takes Place: Giles County and Montgomery County

Program Contact Person: Bonnie Pack

Program Telephone Number: (703) 382-8835

Brief Description of the Program: The Nurturing Program is a highly structured 15 to 20 week parenting program for teen parents of infants and toddlers. The program is designed to deal with the characteristics of low-income families. Fundamental program structure: a parents educational-support group led by a CSB Prevention Specialist and a children's activity group coordinated by volunteers. Program components include: infant stimulation, positive discipline, nutrition, and child development. Referrals primarily originate from department of social services/child protective services, health department, and school personnel.

Shaken Infant Public Education Program

Target Population: Parents, (high-risk) teens, young, single parents under stress, child care providers, medical personnel, and social workers

Agency Responsible For This Program: Prince William County Community Services Board

City/County Where This Program Takes Place: Prince William Area

Program Contact Person: Linda Certa

Program Telephone Number: (703) 335-7730

Brief Description of the Program: (1) Public Education Materials on flyers, bookmarks, fact sheets, TV and radio Public Service Announcements (2) Training Materials - Education Kit, 10 minute training video. Can be used alone or in conjunction with existing parent-infant education programs, parenting programs, child abuse prevention groups, etc.

Welcome Baby Project

Target Population: Adolescent mothers and mothers with mental retardation

Agency Responsible For This Program: Chesterfield Community Services Board

City/County Where This Program Takes Place: Chesterfield

Program Contact Person: Maria Brown, MSW

Program Telephone Number: (804) 271-1214

Brief Description of the Program: The program's mission is to promote optimal child development and a positive relationship between parent(s) and babies through preventing attachment disorders, child abuse and neglect, and unwanted, repeat pregnancies. Both populations are served through home visitations from staff or volunteers up to the child's second birthday.

Prior To Both And During Pregnancy
And
Infancy/Childhood/AdolescencePrevention Programs/Projects

Hand-In-Hand

Target Population: Pregnant teens, and other first-time pregnant women at high risk

Agency Responsible For This Program: Rockingham Memorial Hospital

City/County Where This Program Takes Place: Harrisonburg and surrounding counties

Program Contact Person: Amy J. Schultz, Coordinator

Program Telephone Number: (703) 433-4554

Brief Description of the Program: Hand-in-Hand attempts to decrease infant mortality and morbidity; to improve the quality of parenting; and to increase the use of community services. Trained mentors volunteer to work with these mothers during and after pregnancy to assist them in getting adequate prenatal care, developing parenting skills, and in planning for the completion of their education.

Mental Retardation Prevention

Target Population: Substance abusing adults in a 28-day residential program

Agency Responsible For This Program: Portsmouth Community Services Board

City/County Where This Program Takes Place: Portsmouth

Program Contact Person: Candice Anglin

Program Telephone Number: (804) 393-8618

Brief Description of the Program: Overview of causes of mental retardation prevention, two handicap awareness activities, highlight how their behavior and choices impact on fetal growth and development as well as infants and children (Fetal Alcohol Syndrome, Shaken Baby, Sexually Transmitted Diseases, etc) are dealt with in this program.

MOMS Project

Target Population: Pregnant and postpartum substance abusing moms

Agency Responsible For This Program: Prince William County Community Services Board, Division of Substance Abuse Services

City/County Where This Program Takes Place: Prince William County (sites located in Manassas and Dumfries)

Program Contact Person: Keith Shuster

Program Telephone Number: (703) 335-7800

Brief Description of the Program: This is a one year federally funded grant project. Therapists and aides in each office will provide intensive outpatient substance abuse treatment services, education about parenting, nutrition and sex education, access to prenatal care for clients who qualify, linkage to the local infant intervention program, intensive case management, transportation, and access to child care.

Mother/Mentor

Target Population: Teenagers with their babies birth to 18 months

Agency Responsible For This Program: Rappahannock Area Community Services Board

City/County Where This Program Takes Place: Counties of Caroline, King George, Spotsylvania, and Stafford and City of Fredericksburg

Program Contact Person: Joanne Price

Program Telephone Number: (703) 371-2712

Brief Description of the Program: Volunteers are trained to meet with the pregnant teenager or the new teen mom on a weekly basis. Volunteers will encourage positive interaction, stimulation, and parenting skills between teenage mom and her baby while also tracking baby's development.

Project: Jump Start

Target Population: High-risk mothers and families with emphasis on adolescents, substance-abusing mothers, mothers with psychiatric diagnosis or mental retardation

Agency Responsible For This Program: Western Tidewater Community Services Board

City/County Where This Program Takes Place: Western Tidewater - Suffolk, Franklin, Isle of Wight County, Southampton County

Program Contact Person: M.E. Tetrick (or Clover Watson)

Program Telephone Number: (804) 925-2456

Brief Description of the Program: In-home, community based parenting education and support program focusing on the prenatal and infancy periods. Staff provide education in areas focussing on the importance of nutrition and health care for both mothers and children; the impact of alcohol and other drugs on the developing fetus, developmental stages of childhood and behavioral expectations, effective discipline, etc. Linkage to other services including MH/MR/SAS services is provided; as well as an available emotional support system.

Project LINK

Target Population: Substance using/abusing pregnant and postpartum women and their infants

Agency Responsible For This Program: Interagency model but Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Serivces provides state coordination.

City/County Where This Program Takes Place: 5 sites in Virginia - Newport News, Virginia Beach, Roanoke Area, Charlottesville Area, and Rappahannock Area

Program Contact Person: Susan Geller

Program Telephone Number: (804) 786-1530

Brief Description of the Program: Project LINK is a community-based interagency model to provide coordinated services to meet the multiple needs of substance using/abusing pregnant and postpartum women and their infants. The project involves health care, substance abuse services, infant early intervention services, and parent education. Child care and transportation are provided. Project LINK is comprehensive, including prevention, public education, early intervention, treatment, and support services.

Resource Mothers Program

Target Population: Pregnant and parenting teenagers - some programs also serve older women

Agency Responsible For This Program: Virginia Department of Health in partnership with various community agencies

City/County Where This Program Takes Place: There are 15 or more programs across the state. The Division of Maternal and Child Health of the Department of Health funds Resource Mothers Programs serving Lee County, Bristol, Washington County, Giles County, Pulaski County, Radford, Roanoke City, Fairfax County, Richmond City, Newport News, Hampton, Norfolk, Accomack County, and Northampton County

There are other Resource Mothers Programs serving Rockingham County, Harrisonburg, Henry County, Martinsville, Halifax County, South Boston, Stafford County, Fredericksburg, King George County, Spotsylvania County, Caroline County, Portsmouth, and Virginia Beach.

Program Contact Person: Mary M. Carpenter

Program Telephone Number: (804) 786-7367

Brief Description on the Program: The Resource Mothers Program recruits lay women from the community and provides them with training to serve as "resource mothers" for pregnant and parenting teens. The resource mother becomes a support person for the teenager and her family and, through a plan of scheduled home visits, carries out the following responsibilities:

- identifying pregnant teens and getting them into prenatal care early;
- assisting teens in obtaining Medicaid, WIC, family planning, education, and other community services;
- ensuring teens and infants keep health care appointments, providing help with transportation and babysitting if needed; and
- reinforcing recommendations of health care providers and giving basic health information and advice in areas such as nutrition, avoidance of smoking and alcohol, infant development, and infant care.

ACTION FOR PREVENTION, INC.

Action for Prevention, Inc. is a voluntary non-profit organization whose purpose is to promote the prevention of developmental disabilities in Virginia. Membership in Action for Prevention (AFP) includes public and private sector representatives from the health, education, social services, mental health, and rehabilitation fields. Parents of children with disabilities are represented as well as other interested Virginians.

AFP provides educational opportunities to professionals or volunteers through seminars, conferences, newsletters, and other meetings. AFP's major goal however, is to identify critical areas in the prevention of developmental disabilities and to develop strategies to address these areas.

AFP was founded in 1983 following a statewide mental retardation/developmental disabilities prevention conference. That conference produced our Action Agenda of over 100 recommendations and AFP was established to ensure that these recommendtaions were carried out. The Action Agenda was updated in 1989 to reflect new findings and new problems.

Members choose their degree of involvement. Some participate actively on one of the committees, attend AFP meetings, participate on a 30 member Board, help in public information campaigns, or work with the state and local government. Others simply choose to learn more about prevention by receiving Action for Prevention's newsletters and bulletins.

For more information write:

Action for Prevention, Inc.
P.O. Box 11446
Richmond, VA 23230

Developmental Disabilities Prevention Programs/Projects

Name of Program:_____

Target Population:_____

_____

Agency Responsible For This Program:_____

_____

City/County Where This Program Takes Place:_____

_____

Program Contact Person:_____

Program Telephone Number:_____

Brief Description of the Program:_____

_____

_____

_____

_____

Is the Program Research Based And/Or Have an Evaluation Component? If So,

Briefly Describe:_____

_____

Please complete this form and use additional pages if needed. **Please respond by June 30, 1992.**

Send to: Elizabeth B. Whitley, Ph.D.
VIDD
301 W. Franklin St., Box 3020
Richmond, VA 23284-3020

My signature gives permission to use this information in the manual and/or share with others upon request.

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